

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



LSHTM Research Online

Chin Lim, Wan; (2011) Understanding the concept of health related quality of life in adult, general critical care survivors. PhD thesis, London School of Hygiene & Tropical Medicine. DOI: <https://doi.org/10.17037/PUBS.00682439>

Downloaded from: <https://researchonline.lshtm.ac.uk/id/eprint/682439/>

DOI: <https://doi.org/10.17037/PUBS.00682439>

Usage Guidelines:

Please refer to usage guidelines at <https://researchonline.lshtm.ac.uk/policies.html> or alternatively contact researchonline@lshtm.ac.uk.

Available under license. To note, 3rd party material is not necessarily covered under this license: <http://creativecommons.org/licenses/by-nc-nd/3.0/>

<https://researchonline.lshtm.ac.uk>

Understanding the Concept of Health Related Quality of Life in Adult, General Critical Care Survivors

A thesis submitted for the Degree of Doctor of Philosophy


Wan Chin Lim

Faculty of Public Health and Policy

London School of Hygiene and Tropical Medicine

Statement of own work

I, Wan Chin Lim, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature


Acknowledgements

I couldn't have completed this PhD without help and support from the people around me. Special thanks goes to:

My supervisor, Professor Nicholas Mays, for his constant guidance and his tireless patience throughout the PhD. I could not have asked for a better supervisor to guide my toddling into the research world.

My associate supervisor, Professor Donna Lamping, for helping me better understand some of the technical aspects of health related quality of life measurement.

Professor Nicholas Black and Professor Kathy Rowan for taking precious time out of their busy schedules to provide advice and feedback about the PhD. I also want to especially thank Kathy for her thoughtful mentoring – I didn't just learn how to conduct research from her, I learnt how to do life.

Professor John Cairns, Dr. Sarah Smith and Dr. Claire Snowdon for their helpful insights and comments during my upgrading review.

Dr. Huw Maddock and Dr. Christina Jones, for their help in identifying and recruiting study participants. I also want to thank Christina for sharing her considerable expertise with critical care survivors with me. The study couldn't have been conducted without them.

Ms. Lisa Hinton, for being such an effective sounding board when I first started my coding.

All the study participants, for so willingly sharing their stories.

Dr. Philip Haji-Michael, for all the help he rendered in the organisation of my clinical hours, such that I would have ample time for my PhD.

The staff at Intensive Care National Audit & Research Centre (ICNARC), for their prompt assistance in everything requested of them, from providing some desk

space to querying the ICNARC database to help my thoughts with the study sample.

Intensive Care Foundation (Intensive Care Society), for assisting with some of the research costs of this study.

My husband, Dr. Matthew Cove, for living with my obsession with the PhD so graciously and loving me through the very trying analysis and writing-up process.

My parents, for their generous support and unwavering love throughout my life. I wouldn't even have started this PhD without their encouragement to live my dreams.

My sister, Ms. Wan Yong Lim and my dear friend, Dr. Ching Wan Chan, for enduring my very first drafts and providing insights into how I can report my findings and explain my ideas more clearly.

Many of my friends (too numerous to name individually – you know who you are!!), for all the encouragement, practical help and prayerful support that they have provided me during the entire PhD journey.

Last but not least, I want to give thanks to the Lord Jesus who answers prayers, for as usual, He was 'able to do immeasurably more than all we ask for or imagine' (Ephesians 3:20 NIV).

Abstract

Background

Health related quality of life (HRQoL) is an important outcome to assess in adult, general critical care survivors¹. There are two expert consensus generic HRQoL measures-the SF-36 and EQ-5D-for this population, but there is still no agreed specific measure, despite the move towards using a combination of generic and specific measures in many other areas of health care.

To address this gap, the research aims, first, to understand and define the concept of HRQoL from the perspective of survivors and second, to determine the extent to which the current expert consensus generic measures capture survivors' HRQoL, so that recommendations concerning a critical care-specific measure can be made.

Methods

Semi-structured interviews were conducted using two strategies of data collection; an in-depth semi-structured interview based on a topic guide and a 'questerview'² (1), a form of cognitive debriefing that used either the SF-36 or the EQ-5D to trigger narratives.

Results

Based on study findings, it is recommended that the critical care-specific measure contain general questions that assess:

- Survivors' emotional/psychological and cognitive statuses.
- The following effects of survivors' personal status:
 - Certain restrictive effects of physical status and emotional/psychological status on activities and behaviours.
 - Increases in activities and behaviours caused by physical status and emotional/psychological status.
 - Impact of cognitive status on activities and behaviours (both restrictions and increases).
 - Impact of personal status on: perception of, interpretation of, and responses to life; personality; external appearance; physical zone of comfort and/or activity;

¹ The rest of this document uses either 'critical care survivors' or 'survivors' to refer to adult, general critical care survivors.

² A term coined by Adamson et al. to describe the use of standard measures within in-depth interviews 1. Adamson J, Goberman-Hill R, Woolhead G, Donovan J. 'Questerviews': using questionnaires in qualitative interviews as a method of integrating qualitative and quantitative health services research. *Journal of Health Services Research and Policy*. 2004 Jul;9(3):139-45.

suitability and availability of clothes; interactions and relationships with others; place of residence; and finances.

To further refine the measurement of survivors' HRQoL, this measure should also: (i) specifically capture survivors' perceptions of the pertinent changes after critical illness; (ii) accurately reflect fluctuating changes; and (iii) encourage survivors to provide relevant information.

Contents

1. Background.....13

1.1 Introduction13

1.2 Why measuring HRQoL in critical care matters.....13

1.3 Measurement of HRQoL in critical care survivors.....13

1.3.1 Key Review findings21

2. Literature review and the development of a preliminary conceptual framework for HRQoL of critical care survivors27

2.1 Introduction27

2.2 Methods used in the development of the preliminary conceptual framework for HRQoL of critical care survivors.....27

2.2.1 Identification of changes/issues/domains that might influence survivors’ HRQoL.....27

2.2.2 Usage of the literature review and qualitative interviews in the generation of the preliminary conceptual framework29

2.2.3 Construction of the preliminary conceptual framework for HRQoL of critical care survivors.....30

2.3 Preliminary conceptual framework for HRQoL of critical care survivors.....36

2.4 Conclusion.....38

3. Qualitative interview methods and study participants.....39

3.1 Introduction39

3.2 Qualitative interview methods.....39

3.2.1 Sampling strategy40

3.2.2 Recruitment strategy.....42

3.2.3 Structure and format of interviews43

3.2.4 Data analysis.....46

3.3 Profile of study participants48

3.3.1 Demographic profile48

3.3.2 Details of critical illness.....51

3.3.3 Individual profiles of study participants53

3.4 An overview of what constitutes HRQoL for critical care survivors.....58

3.5 Conclusion.....59

4. Survivors’ physical status and its impact.....60

4.1 Introduction60

4.2 Description of survivors’ physical status60

4.3 Impact of survivors’ physical status.....63

4.3.1 Physical appearance.....67

4.3.2 Activities and behaviours.....67

4.3.3 Physical zone of activity81

4.3.4 Suitability and availability of clothes81

4.3.5 Interactions and relationships with others82

4.3.6 Place of residence84

4.3.7 Finances.....85

4.3.8 Other aspects of a survivor’s personal status.....86

4.4 Conclusion.....87

5. Survivors’ emotional/psychological status and its impact.....89

5.1 Introduction89

5.2 Description of survivors’ emotional/psychological status89

5.3 Impact of survivors’ emotional/psychological status93

5.3.1 Perception of, interpretation of, and responses to life.....95

5.3.2 Personality99

5.3.3 Physical appearance.....100

5.3.4 Activities and behaviours.....101

5.3.5 Physical zone of comfort and/or activity112

5.3.6 Interactions and relationships with others116

5.3.7 Other aspects of a survivor’s personal status.....124

5.4 Conclusion.....124

6. Survivors’ cognitive status and its impact.....127

6.1 Introduction127

6.2 Description of survivors’ cognitive status.....127

6.3 Impact of survivors’ cognitive status131

6.3.1 Perception of, interpretation of, and responses to life.....132

6.3.2 Personality134

6.3.3 Activities and behaviours.....135

6.3.4 Physical zone of comfort and/or activity144

6.3.5 Interactions and relationships with others144

6.3.6 Other aspects of a survivor’s personal status.....146

6.4 Conclusion.....149

7. The role of contextual and personal factors.....151

7.1 Introduction151

7.2 Contextual factors151

7.2.1 Contextual backdrop of critical illness.....151

7.2.2 Context surrounding the consequences of critical illness.....153

7.3 Personal factors158

7.4 Conclusion.....160

8. Content mapping between expert consensus generic measures and patient-based conceptual framework for survivors’ HRQoL162

8.1 Introduction162

8.2 Methods.....162

8.2.1 Construction of final, patient-based conceptual framework162

8.2.2 Evaluation of the extent to which the current expert consensus generic HRQoL measures capture the patient-based conceptual framework163

8.3 Patient-based conceptual framework.....163

8.3.1 Conceptual domains that capture the HRQoL of critical care survivors...165

8.3.2 Relationship of contextual and personal factors to patient-based conceptual framework167

8.4 How well does the current expert consensus generic measures capture survivors’ HRQoL?168

8.4.1 Content mapping between the SF-36 and the patient-based conceptual framework.....171

8.4.2 Content mapping between the EQ-5D and the patient-based conceptual framework.....190

8.5 Conclusion.....200

9. Other considerations in relation to the content of a critical care-specific measure202

9.1 Introduction202

9.2 Methods used to identify concerns that have relevance for the content of a critical care-specific measure202

9.3 Other concerns that have implications for the content of a critical care-specific measure.....202

9.3.1 The importance of capturing survivors' perceptions.....	202
9.3.2 Level of detail and specification	206
9.3.3 The measurement of temporal changes.....	209
9.3.4 The elicitation of sensitive information	210
9.4 Conclusion.....	214
10. Conclusion and recommendations.....	215
10.1 Introduction	215
10.2 Recommended requirements for a critical care-specific measure.....	215
10.2.1 Domains and sub-domains that should be covered.....	215
10.2.2 Other recommended requirements.....	217
10.3 Strengths and limitations of study	217
10.3.1 Strengths of study	217
10.3.2 Limitations of study	225
10.4 What the study adds to current knowledge.....	234
10.5 Recommendations for future research	237
10.6 Conclusion.....	239
Bibliography	240
Appendix A.....	253
List of outcome studies included in literature review	254
Appendix B	262
Letter of invitation for study participants.....	263
Patient information sheet.....	264
Consent form.....	268
Letter to GP	269
Appendix C.....	270
Topic guide (including appendix to topic guide).....	271
SF-36.....	276
EQ-5D.....	281

List of Tables

1.1 Psychometric properties and their tests.....16

1.2 Evidence for psychometric properties of generic measures used in critical care...23

1.3 Evidence for psychometric properties of specific measures used in critical care ..24

2.1 Contribution of the literature to the preliminary conceptual framework.....32

2.2 Preliminary conceptual framework for HRQoL in critical care survivors.....36

3.1 Demographics of the study population50

3.2 Details on critical illness52

3.3 Individual profiles of study participants54

4.1 Physical changes experienced by survivors of critical illness60

4.2 Areas that could be affected by a survivor’s physical status63

5.1 Emotional/psychological responses of survivors.....90

5.2 Areas that could be affected by a survivor’s emotional/psychological status94

6.1 Cognitive changes experienced by survivors 129

6.2 Areas that could be affected by a survivor’s cognitive changes 131

8.1 Content mapping between the expert consensus generic measures and the patient-based framework.....169

8.2 Questions in the SF-36171

8.3 Questions of the EQ-5D190

List of Figures

8.1 Patient-based conceptual framework and its relationships with contextual and personal factors164

Chapter 1: Background

1.1. Introduction

The thesis examines the concept of health-related quality of life (HRQoL) and its measurement in adult, general critical care survivors. This chapter considers why it is important to assess survivors' HRQoL as well as reviews the knowledge base with regard to its measurement in this population. It then explores what needs to be done to further advance the science of HRQoL measurement in survivors, before concluding with an overview of how this would be achieved and how the rest of this document would be structured.

1.2. Why measuring HRQoL in critical care survivors matters

Mortality has traditionally been the focus in critical care outcomes research, as critical care therapy is primarily directed at overcoming an acute life-threatening illness (2, 3). It remains a key outcome in critical care outcomes research, because of its simplicity and ease of recording, as well as the fact that it is the only outcome that has been routinely registered over the past 25 years (2, 4).

However, there is increasing recognition that it is no longer appropriate to use mortality as the sole endpoint in critical care outcomes research (3, 5). Mortality rates of critical care patients have been consistently decreasing over time (4). In addition, research has shown that survivors of critical illness are often left with significant persisting problems, and simple mortality statistics, such as 28-day mortality rates, do not capture the cost these problems impose on survivors, their family and friends, and even the wider society (5, 6). Therefore, when assessing outcomes in critical care, it is crucial to measure not only mortality, but to also document endpoints relating to patients who have survived their critical illness.

One of the important non-mortality endpoints to assess in critical care survivors is HRQoL. HRQoL, defined as *"the impact of a perceived health state on an individual's potential to live a subjectively fulfilling life"* (7, p.452), encompasses patients' views of the impact of disease and medical interventions on aspects of health that influence their quality of life (QoL) (2, 8-13). In that respect, the information that HRQoL provides has great relevance for patients, families, funders and society at large. Therefore, unsurprisingly, HRQoL is considered an essential endpoint to assess when evaluating outcomes in health care (14).

1.3. Measurement of HRQoL in critical care survivors

In many areas of health care, there has been a move towards using a combination of generic and specific measures when evaluating HRQoL. Generic

measures enable direct comparisons of the relative impact of ill health and health care programs between different population groups, because they are widely applicable across different diseases, patients and populations (9, 13, 15). However, they may not address specific areas that are considered to be particularly relevant to HRQoL by patients with certain conditions. Thus, they often provide an incomplete picture on how a certain condition/disease affects a person's QoL and they may not be as sensitive to the changes in HRQoL resulting from specific medical interventions for specific conditions (reduced responsiveness³) (9, 13, 15, 16). In contrast, specific measures tend to be more focused and relevant to the particular group(s) of patients being studied (9, 13, 15). Therefore, not only do they give a more complete picture of the impact of a certain condition/disease on QoL, they are usually more sensitive to "clinically important" changes (9, 13, 15, 16). The respective (and complementary) advantages of generic and specific measures makes employing them in tandem very effective when it comes to the application of HRQoL measurement.

At present, there are two expert consensus generic measures-the SF-36 and EQ-5D-for use in the critical care population, although the experts (in critical care) who have reached this consensus have acknowledged that the evidence for this consensus was limited and encouraged further research into the evaluation of HRQoL instruments in this population group (5). Their choice of measures was made on the basis that the two chosen instruments had been extensively validated in many other patient populations, were straightforward to administer and were applicable to different countries and languages (5). In addition, both instruments could be used to generate utilities (5), which were essentially valuations attached to given health states (17). These utilities could in turn be used for the calculation of quality adjusted life years gained (QALYs), a key measure used in cost effectiveness analyses (5). In light of these reasons and the paucity of research on the psychometric properties (listed in Table 1.1) of HRQoL measures in this population at the time of the consensus, the SF-36 and EQ-5D were reasonable choices as generic measures for the critical care population.

However, currently, there is still no agreement regarding the specific measure(s) that should be used in this population group. With this in mind, I carried out a review of the literature with the following objectives:

³ Areas that are relevant are very often also the areas that are targeted for change by interventions. It is, therefore, not surprising that the omission of these areas result in the measures being less sensitive to changes in HRQoL.

1. To identify measures that have been used to evaluate HRQoL in critical care survivors
2. To evaluate the measures identified in Objective 1 against the appraisal framework in Table 1.1 using the available literature.
3. To delineate the issues that need to be addressed to move forward with regard to reaching a consensus on a critical care-specific measure.

Table 1.1: Psychometric properties and their tests

Psychometric property	Definition/Test	Criteria for Acceptability
Acceptability	Quality of data; assessed by completeness of data and score distributions.	Applied to items: Missing data <5%. Even distribution of endorsement frequencies across response categories with maximum endorsement frequencies <80% (i.e. the proportion of respondents who endorse each response categories), including floor/ceiling effects <80% (i.e. response categories with high endorsement rates at the bottom/top ends of the scale respectively). Applied to summary scores: Missing data <5%. Floor/ceiling effects <80%. Skewness values between +1 to -1.

Psychometric property		Definition/Test	Criteria for Acceptability
Reliability			
<ul style="list-style-type: none"> Internal consistency 		Extent to which items comprising a scale measure the same construct (e.g. homogeneity of the scale); assessed with Cronbach's alpha coefficients and item-total correlations.	<ul style="list-style-type: none"> Cronbach's alpha coefficients for summary scores >0.70. Item-total correlations ≥ 0.20.
<ul style="list-style-type: none"> Test-retest reliability 		The stability of measuring instruments; assessed with administering instruments on respondents on two different occasions and examining correlation between test and retest scores ⁴ (when the measure is interviewer or clinician rated, test-retest reliability typically refers to agreement among two or more observers).	<ul style="list-style-type: none"> Test-retest reliability correlations for summary scores ≥ 0.70 for group comparisons.

⁴ Length of test-retest interval must be short enough to ensure that change in variable being measured is unlikely to have occurred but sufficiently long to ensure that respondents do not recall their responses from first assessment. In the case of HRQoL, an interval of 2-14 days has been suggested.

Psychometric property	Definition/Test	Criteria for Acceptability
Validity		
<ul style="list-style-type: none"> Content validity 	<p>The extent to which the content of a scale is representative of the conceptual domain it is intended to cover; assessed qualitatively during the questionnaire development stage through individual interviews and/or focus group discussions involving patients, pre-testing with patients, expert opinion and literature review.</p>	<p>Qualitative evidence from interviews involving patients, either as individuals or in focus groups, pre-testing with patients, expert opinion and literature review that items in the scale are representative of HRQoL in adult critical care survivors.</p>
<ul style="list-style-type: none"> Construct validity <ol style="list-style-type: none"> Within scale analysis 	<p>Evidence that a single entity (construct/dimension) is being measured and that items can be combined to form a summary score; assessed on the basis of evidence of good internal consistency and correlations between scale scores.</p>	<p>Internal consistency (Cronbach alpha coefficient) >0.70. Item/total correlations ≥ 0.20. Evidence from factor analysis that a single construct is being measured.</p>

Psychometric property	Definition/Test	Criteria for Acceptability
2. Analysis against external criteria		
– Convergent/Discriminant	<p>Convergent: evidence that scale is correlated with other measures of the same/similar constructs in the hypothesised direction; assessed on the basis of correlations between the measure and other similar measures.</p> <p>Discriminant: evidence that scale is not correlated with other measures of different constructs; assessed on the basis of correlations with measures of different constructs.</p>	<p>Correlations are expected to vary according to the degree of similarity between constructs that are being measured by each instrument. Specific hypotheses are formulated and predictions tested on the basis of correlations.</p>
– Known differences/hypothesis testing	<p>The ability of the scale to differentiate known groups; assessed by comparing scores for subgroups who are expected to differ on the construct being measured.</p>	<p>Significant differences between known groups and/or a difference of expected magnitude. Specific hypotheses are formulated and predictions tested on the basis of correlations.</p>

Psychometric property	Definition/Test	Criteria for Acceptability
Responsiveness	The ability of a scale to detect significant change over time; assessed by comparing scores before and after an intervention of known efficacy (on the basis of various methods including t-tests, effect sizes, standardised response means or responsiveness statistic).	Statistically significant change in scores from pre- to post-treatment and/or a difference of expected magnitude.

Adapted with permission from Lamping et al. (2002) and Lamping et al. (2003) (16, 18).

Studies were identified through:

- Searching of the electronic databases, Medline and Embase, using the search software, Ovid Gateway. The following search terms were used in the search:
 - Intensive care, critical care, intensive therapy, high dependency, intermediate care.
 - Outcome measure, follow-up, health status, functional status, sequelae, quality of life, health-related quality of life, impairment, morbidity.
- Checking the reference lists of published reviews.
- Snowballing from reference lists of relevant studies.

Studies were included for review if they met the following inclusion criteria:

1. The study involved a measure that had been used on at least 2 separate occasions⁵.
2. The study involved a population of adult critical care survivors (defined as a population consisting mainly of patients from critical care which are ≥ 16 years of age) with a length of stay of >24 hours.
3. Data on patients' HRQoL after discharge from adult critical care were included.
4. The report of the study was published in English.

For the purposes of Objective 2, studies were included only if in addition to the above four criteria, they stated clearly that part of the goal of the research was to evaluate whether the HRQoL measure(s) used fulfilled one/more of the criteria listed in Table 1.1.

The next subsection summarises the key findings from the review as well as the conclusions drawn from reviewing the literature.

1.3.1. Key review findings

Using the aforementioned search strategy and inclusion criteria, the review identified 11 separate measures used in 96 outcome studies⁶ in critical care, up till August 2005. Some of these outcome studies used more than one measure.

Given the heterogeneity of the critical care population, most measures used in

⁵ There were many questionnaires that had been used only once in the critical care literature. Although they were said to measure HRQoL, many were actually a series of unvalidated questions that authors felt were important to ask patients when assessing HRQoL. Therefore, strictly speaking, they cannot be classified as HRQoL measures. Furthermore, none of the studies involving such questionnaires were methodologically robust enough to answer the question of whether the instrument is valid for use in the critical care population.

⁶ Complete reference list for studies is in Appendix A.

this population group were generic measures, which are applicable for use across a wide variety of conditions and patient populations with different diseases and conditions. Measures specific to critical care were used less frequently. As to be expected, the content of these specific measures overlaps somewhat with generic measures, because any measure developed for use in this population group has to capture HRQoL in a very heterogeneous population.

For all the measures identified in this review, evidence on their properties (as per Table 1.1) in critical care survivors were collected and reviewed. This information was collected from reviewed studies that included an assessment on whether the HRQoL measure(s) used fulfilled one/more of the criteria listed in Table 1.1. The available evidence is collated in Table 1.2 (generic measures) and Table 1.3 (specific measures).

Table 1.2: Evidence for psychometric properties of generic measures used in critical care

	SF-36	EQ-5D	SIP/FLP	NHP	Rosser's Distress Categories	Disability and	Spitzer's Quality of Life Index and Uniscale	PGWB
Number of studies using measure	33	11	26	14	5		7	3
Number of studies evaluating measure ⁷	5	2	6	2	1		0	1
Criteria								
1. Acceptability	-	-	0	--	0		0	0
2. Reliability								
• Internal consistency	++	0	0	0	0		0	0
• Test-retest reliability	++	0	0	0	0		0	0
3. Validity								
• Content validity	-	0	--	0	0		0	0
• Construct validity								
i. Within scale analysis	0	0	+	0	0		0	0
ii. Analysis against external criteria								
- Convergent/discriminant	++	++	+/-	++	+		0	+
- Known group differences/hypothesis testing	++	0	0	0	0		0	0
4. Responsiveness	0	0	0	0	0		0	0

++: evidence for; +: weak evidence for; +/-: equivocal/conflicting evidence; -: weak evidence against, --: evidence against; 0: no evidence.

⁷ These were the studies that expressly specified that one of their study objectives was to evaluate whether the HRQoL measure(s) used in their research fulfilled one or more of the criteria set out in Table 1.1.

Table 1.3: Evidence for psychometric properties of specific measures used in critical care

	PQoL	Fernandez's questionnaire (or SP)	QOL-Whiston Hospital Questionnaire	QOL-IT
Number of studies using measure	13	5	5	2
Number of studies evaluating measure ^a	4	2	1	1
Criteria				
1. Acceptability	0	0	0	0
2. Reliability				
• Internal consistency	++	++	0	++
• Test-retest reliability	0	++	0	++
3. Validity				
• Content validity	0	+	0	0
• Construct validity				
i. Within scale analysis	0	++	0	0
ii. Analysis against external criteria				
- Convergent/discriminant	+	++	++	++
- Known group differences/hypothesis testing	0	++	0	0
4. Responsiveness	0	0	0	0

++: evidence for; +: weak evidence for; +/-: inconsistent evidence; -: weak evidence against; --: evidence against; 0: no evidence.

^a These were the studies that expressly specified that one of their study objectives was to evaluate whether the HRQoL measure(s) used in their research fulfilled one or more of the criteria set out in Table 1.1.

From the literature review, it was clear that a number of different HRQoL measures had been used in the critical care population, all of which had been used with very limited information on their psychometric properties in critical care survivors. Despite the experts' call for more research into the psychometric properties of HRQoL measures in survivors, most of the instruments used had had a minimum amount (if any) of such evaluation. Even the SF-36 had not been fully evaluated, although it had been used in the most studies consequent to being one of the expert consensus generic measures for this population.

In particular, there was a profound lack of data on the content validity of HRQoL measures used in critical care. Some studies had applied existing HRQoL measures without ensuring that the domains/dimensions covered in these measures were relevant and appropriate for critical care patients (12). Others had developed measures using a "top-down" approach. This was when the conceptualisation and operationalisation of HRQoL were informed purely by a review of the literature and of the content of existing instruments with expert input from clinicians and researchers, but no input from patients (17).

Without any direct patient input, content validity might be compromised due to the exclusion of relevant topics (such as intrusive memories of the critical care experience or frequent nightmares) (17). As an illustration, Hulsebos et al., when using the SIP to evaluate survivors' HRQoL, found that the items were inappropriate for very serious illness related disturbances (19). The example they gave was that asking about urinary control was not very appropriate for survivors without a bladder. Furthermore, the items included in the different scales of the instruments might not cover the range needed to fully capture survivors' HRQoL or discriminate well between the different levels of HRQoL experienced by this population. As it stands, there had been some evidence to suggest that the measurement models of the existing measures might not be suitable for this patient group. For instance, Chrispin et al. reported significant floor and ceiling effects in the SF-36 while Kaarlola et al. noted a ceiling effect in the EQ-5D when using these measures in survivors (20, 21).

To move towards a consensus on the critical care-specific measure, it is vital that this particular gap is addressed, which, in turn, calls for an understanding of what constitutes HRQoL in the eyes of survivors themselves. To further clarify the requirements for a critical care-specific measure, it would be helpful to evaluate the extent to which the expert consensus generic measures are sufficient in measuring survivors' HRQoL. Not only would this identify the aspects of HRQoL that would

particularly need to be captured in a critical care-specific measure, it would also yield insights into (some of) the other issues that need to be considered and/or addressed for a questionnaire to capture survivors' HRQoL more effectively.

Therefore, the two main aims of the study described in this thesis were:

1. To understand and define the concept of HRQoL from the perspective of critical care survivors; and
2. To determine the extent to which the current expert consensus generic measures capture HRQoL in critical care survivors and make recommendations concerning a critical care-specific measure accordingly.

To accomplish these aims, I sought to fulfill the following objectives in the study:

1. To develop a preliminary conceptual framework for HRQoL survivors from the existing evidence (Chapter 2).
2. To identify critical care survivors and seek their views on areas that matter to them, particularly in relation to the impact of critical illness on them and their lives (Chapter 3).
3. To report the changes and areas that are important to critical care survivors in terms of their HRQoL (Chapters 4-7).
4. To finalise a patient-based conceptual framework for HRQoL of critical care survivors and evaluate the extent to which the expert consensus generic measures capture this framework (essentially a representation of survivors' HRQoL) (Chapter 8).
5. To highlight (some of) the other considerations related to the content of questionnaires (i.e. other than the aspects of HRQoL that particularly need to be captured) when such questionnaires are being used to assess survivors' HRQoL (Chapter 9).
6. To make recommendations with regard to a specific HRQoL measure for critical care survivors (Chapter 10).

Chapter 2: Literature review and the development of a preliminary conceptual framework for HRQoL of critical care survivors

2.1. Introduction

To prepare for the process of eliciting survivors' views on what constituted HRQoL for them, a preliminary conceptual framework for their HRQoL was developed. This framework gave some insight into the issues that might arise during the interviews. In addition, it served as an aid for the qualitative work carried out in the study; it was used, whenever necessary, to help steer and structure the in-depth face-to-face interviews conducted with survivors to seek their views on what mattered to them in terms of their HRQoL.

This chapter discusses the methods used to develop this framework and presents the detailed content of the framework.

2.2. Methods used in the development of the preliminary conceptual framework for HRQoL of critical care survivors

2.2.1. Identification of changes/issues/domains that might influence survivors' HRQoL

Changes/issues/domains that might be of importance to survivors' HRQoL were identified by:

1. A review of the relevant scientific and lay literature.
2. Utilising audio and video recordings of forty narrative interviews with critical care survivors (conducted by the Health Experiences Research Group in Oxford), alongside the written transcripts of these interviews.

The rest of this section first explores each method in turn. It then details the process of how each method is used to identify the changes/issues/domains that might be of significance to survivors' HRQoL.

A. Literature Review

Both the scientific and lay literature was examined to help determine the changes/issues/domains that may be of relevance to survivors' HRQoL. A review of the scientific literature in the English language was conducted to identify:

1. Research and discussion articles on the domains that constitute HRQoL⁹, in general.
2. Quantitative and qualitative studies, discussion pieces/reviews and individual

⁹ The literature indicates that there is no real consensus on which domains HRQoL should definitely include. However, this debate is beyond the scope of this study and is not discussed further here.

case reports that provide insights into the views and experiences of critical care survivors in relation to their HRQoL.

Electronic databases, namely Medline and EMBASE, were searched using the search software, Ovid Gateway, and the following search terms:

- Intensive care, critical care, intensive therapy, high dependency, intermediate care.
- Outcome measure, follow-up, health status, functional status, sequelae, quality of life, health-related quality of life, impairment, morbidity, recovery experiences, experience, aftercare.
- Qualitative, qualitative research, interviews, questionnaires.

Snowballing from reference lists of relevant articles was also undertaken.

Alongside the review of scientific literature, a review of the lay literature in the public domain was also carried out. A search of the World Wide Web was conducted with Google, using search terms such as

- Intensive care, critical care, intensive therapy, high dependency, intermediate care.
- Recovery experiences, experiences, aftercare, follow-up.

Websites on critical illness, information booklets on critical care, and personal accounts on the Internet were all included. In addition, through my own work as a critical care doctor, I was able to gain access to information booklets from some hospitals (that were not on the internet). These were also included in the literature review of the lay literature.

Although no previous research had been carried out specifically to investigate the conceptualisation and operationalisation of HRQoL in critical care survivors, the review of the relevant scientific and lay literature shed some initial light on how survivors might view the concept of HRQoL. It delineated (some of) the changes and issues that were experienced by survivors. In addition, the review also identified the domains/dimensions commonly used in the measurement of HRQoL and in doing so, helped classify the changes and issues experienced by survivors into possible domains/dimensions of HRQoL.

Individual case reports from the scientific literature as well as information from the lay literature were particularly useful in this initial, preliminary conceptualisation and operationalisation of survivors' HRQoL. Much of the information from these sources was from individuals who had gone through an episode of critical illness and consisted of personal accounts reflecting on the critical illness experience. There was

minimal interference with the survivors' viewpoint, which made information from such sources an invaluable resource when seeking to understand and define the concept of HRQoL from the perspective of survivors.

The knowledge gleaned from the literature review, along with the information from interviews conducted with survivors by the Health Experiences Research Group (see next subsection), contributed to the preliminary conceptual framework for HRQoL of critical care survivors (Table 2.2).

B. Qualitative interviews undertaken by the Health Experiences Research Group

Besides the literature review, forty narrative interviews with critical care survivors were also used to identify the changes/issues that might potentially affect survivors' HRQoL. These interviews were conducted by the Health Experiences Research Group, based at the University of Oxford. This Research Group, together with DIPEX (Directory of Patient Experience Project) and the related websites (www.healthtalkonline.org and www.youthhealthtalk.org), aims to inform the public and health professionals of the wide variety of personal experiences of health and illness associated with different conditions. To ensure a wide range of experiences and views, the Health Experiences Research Group used a maximum variation sample in their research.

Permission to use video and audio copies and written transcripts of the data for this current study was obtained from the research director, Dr. Sue Ziebland. All interviews conducted by the Health Experiences Research Group have consent for use in secondary research approved by a multicentre research ethics committee (MREC).

These interviews from the Health Experiences Research Group database drew on survivors' experiences through all phases of critical illness, from the time they were admitted to a critical care unit right through to when they had recovered. Given that these interviews contained some data on the recovery phase of the illness, they were extremely useful when it came to identifying the changes/issues that may influence the HRQoL of this population. The relevant data were extracted by listening to the interviews carefully as well as reading and re-reading the transcripts.

2.2.2. Usage of the literature review and qualitative interviews in the generation of the preliminary conceptual framework

The exercise of using the literature and qualitative interviews to identify the changes/issues/domains of potential importance to survivors' HRQoL and thus generate the preliminary conceptual framework was not a linear process, but rather, an iterative one.

First, the literature, especially the scientific literature, was reviewed to delineate the domains/dimensions commonly used in the conceptualisation and operationalisation of HRQoL. It was also used to determine (some of) the changes and issues encountered within each of the domains/dimensions.

The qualitative interviews conducted by the Health Experiences Research Group were then used to establish an understanding of (some of) the detailed changes and issues that might be of relevance to survivors' HRQoL from their viewpoint. In particular, data from these interviews highlighted the importance of psychological and cognitive changes in the concept of survivors' HRQoL. For instance, psychological changes such as persistent nightmares and flashbacks had an adverse impact on their HRQoL while the ability to make sense of the critical illness and recovery experience constituted psychological recovery and brought about an improvement in their HRQoL. In terms of cognitive changes, memory and concentration problems affected many aspects of their daily lives, such as reading, watching television and the ability to carry out coherent conversations. In addition, survivors also spoke vividly about the various sources of support (including spiritual support) and how they played an important role in influencing their HRQoL. Lastly, whilst the literature did allude to the fact that critical care survivors suffered limitations in their daily lives, many of the more in-depth details about the specific changes in activities and role functioning that seemed to be of importance to survivors were provided by the qualitative interview data.

Finally, the literature, more specifically the individual case reports from the scientific literature and the lay literature, was examined to consolidate the understanding of what constituted HRQoL from the perspective of critical care survivors. This literature further corroborated the fact that although physical changes and issues were universal among critical care survivors, psychological and cognitive changes featured very prominently in the concept of survivors' HRQoL and may be of equal importance (to physical changes and issues) in influencing their HRQoL. As an example, Bowers was a critical care survivor who wrote about her critical illness and recovery experience and she did not just describe the physical changes and issues she experienced after her critical illness but also reported her psychological turmoil and cognitive problems (22).

2.2.3. Construction of the preliminary conceptual framework for HRQoL of critical care survivors

After delineating the changes and issues experienced by survivors, these

changes and issues were organized into domains/dimensions to construct a preliminary conceptual framework for HRQoL of critical care survivors. In order to clearly define the respective contributions made towards the preliminary conceptual framework by the literature review and the interview data, the main findings of the literature review are summarised in the next subsection

A. Contribution of the literature review to the preliminary conceptual framework

As already stated, the literature review informed the preliminary conceptual framework in two different ways. The general HRQoL literature helped establish the domains/dimensions commonly used in the conceptualisation and operationalisation of HRQoL, both in general and in other populations. In addition, there was also a growing body of literature (both scientific and lay literature) that specifically focused on (some of) the key changes and issues experienced by individuals who had survived an episode of critical illness, although not all of this literature gave a clear indication of how such changes and issues contribute to the concept of HRQoL from the perspective of these survivors. Nonetheless, whilst certain types of literature such as individual case reports and personal accounts did shed some light on the changes and issues that may be of importance to the concept of HRQoL from their viewpoint, it was considered premature to only include the changes and issues mentioned in these types of literature. Consequently, it was assumed that every change/issue raised by all the reviewed literature may contribute to survivors' HRQoL and therefore, they were all incorporated into the preliminary conceptual framework.

A synopsis of how the literature contributed to the preliminary conceptual framework alongside the key sources involved is provided in Table 2.1.

Table 2.1: Contribution of the literature to the preliminary conceptual framework

How the literature contributed to the preliminary conceptual framework	Key sources
Domains/dimensions frequently used in the conceptualisation and operationalisation of HRQoL.	<p>1. Selected references from scientific literature:</p> <p>Andresen and Meyers, 2000 (23), Ashing-Gwa, 2005 (24), Bowling, 2001(11), Bowling, 2004 (10), Coons et al., 2000 (25), Fayers and Hayes, 2005 (17), Ferrans et al., 2005 (26), Haywood et al., 2005 (27), Holcik and Koupilova, 1999 (28), Naughton and Shumaker, 2003 (29), Patrick and Bergner, 1990 (30), Stewart and Ware, 1992 (31), Ware, 1995 (32), Ware, 2003 (33)</p>
Specific physical changes and issues experienced by critical care survivors	<p>1. Selected references from scientific literature:</p> <p>Adamson and Elliott, 2005 (34), Angus and Carlet , 2004 (3), Bell and Turpin, 1994 (35), Bowers, 2004 (22), Boyle et al., 2004 (36), Brooks et al., 1997 (37), Broomhead and Brett, 2002 (38), Capuzzo et al., 1996 (39), Capuzzo et al., 2000 (40), Chaboyer and Grace, 2003 (41), Chaboyer, 2006 (42), Culter et al., 2003 (43), Daffurn et al., 1994 (44), Eddleston et al., 2000 (45), Flaatten, 2005 (46), Gardner and Sibthorpe, 2002 (47), Garcia Lizana et al., 2003 (48), Griffiths and Jones, 1999 (49), Griffiths and Jones, 2001 (50), Griffiths et al., 2006 (51), Griffiths and Jones, 2007 (52), Hall-Smith et al., 1997 (53), Hayes et al., 2000 (54), Herridge et al., 2003 (55), Hudson and Brett, 2006 (56), Hurel et al., 1997 (57), Maddox et al., 2001 (58), Moran et al., 2005 (59), Mundt et al., 1989 (60), Rattray and Crocker, 2007 (61), Russell, 1996 (62), Sawdon et al., 1995 (63), Strahan et al., 2003(64), Walling, 2000 (65)</p> <p>2. Information booklets from critical care units and websites.</p>

	<p>3. Websites:</p> <p>http://www.icusteps.org/, http://www.i-canuk.com/default.aspx, http://www.ics.ac.uk/patients_relatives/patients_relatives_section, http://www.ardsusa.org/index.htm</p>
Specific psychological changes and issues experienced by critical care survivors	<p>1. Selected references from scientific literature:</p> <p>Adamson et al., 2004 (66), Adamson and Elliott, 2005 (34), Augus and Carlet, 2004 (3), Bowers, 2004 (22), Brooks et al., 1997 (37), Broomhead and Brett, 2002 (38), Capuzzo et al., 2005 (67), Chaboyer and Grace, 2003 (41), Cuthbertson et al., 2004 (68), Culter et al., 2003 (43), Daffurn et al., 1994 (44), Eddleston et al., 2000 (45), Flaatten, 2005 (46), Garcia Lizana et al., 2003 (48), Gardner and Sibthorpe, 2002 (47), Granja et al., 2005 (69), Griffiths and Jones, 1999 (49), Griffiths and Jones, 2001 (50), Hall-Smith et al., 1997 (53), Hayes et al., 2000 (54), Hough and Curtis, 2005 (70), Hurel et al., 1997 (57), Jones and Griffiths, 2006 (71), Jones et al., 1994 (72), Kapfhammer et al., 2004 (73), Lof et al., 2006 (74), Maddox et al., 2001 (58), Meyer and Hall, 2006 (75), Pattison, 2005 (76), Rattray and Crocker, 2007 (61), Snowdon et al., 1995 (63), Scragg et al., 2001 (77), Walling, 2006 (65)</p> <p>2. Information booklets from critical care units and websites.</p> <p>3. Websites:</p> <p>http://www.icusteps.org/, http://www.i-canuk.com/default.aspx, http://www.ics.ac.uk/patients_relatives/patients_relatives_section, http://www.ardsusa.org/index.htm</p>

Specific cognitive changes and issues experienced by critical care survivors	<p>1. Selected references from scientific literature:</p> <p>Adamson and Elliott, 2005 (34), Angus and Carlet, 2004 (3), Bowers, 2004 (22), Brooks et al., 1997 (37), Broomhead and Brett, 2002 (38), Chaboyer and Grace, 2003 (41), Christie et al., 2006 (78), Eddleston et al., 2000 (45), Gardner and Sibthorpe, 2002 (47), Gordon et al., 2004 (79), Granja et al., 2005 (69), Griffiths and Jones, 2001 (50), Hall-Smith et al., 1997 (53), Hayes et al., 2000 (54), Hopkins and Jackson, 2006 (80), Jones et al., 2006 (81), Meyer and Hall, 2006 (75), Rattray and Crocker, 2007 (61), Rothenhausler et al., 2001 (82), Sukantarat et al., 2005 (83)</p> <p>2. Information booklets from critical care units and websites.</p> <p>3. Websites:</p> <p>http://www.icusteps.org/, http://www.i-canuk.com/default.aspx, http://www.ardsusa.org/index.htm</p>
Specific spiritual changes and issues experienced by critical care survivors	<p>1. Selected references from scientific literature:</p> <p>Adamson et al., 2004 (66), Adamson and Elliott, 2005 (34), Brooks et al., 1997 (37)</p> <p>Maddox et al., 2001 (58), Papathanassoglou and Patiraki, 2003 (84)</p> <p>2. Information booklets from critical care units and websites.</p> <p>3. Websites</p> <p>http://icusteps.org/, http://www.ardsusa.org/index.htm</p>
Specific social changes and issues experienced by critical care survivors	<p>1. Selected references from scientific literature:</p> <p>Adamson et al., 2004 (66), Adamson and Elliott, 2005 (34), Angus and Carlet, 2004 (3), Bell and Turpin, 1994 (35), Brooks et al., 1997 (37), Broomhead et al., 2002 (38), Capuzzo et al., 1996 (39), Capuzzo et al., 2000 (40), Chaboyer and Grace, 2003 (41), Daffurn et al., 1994 (44), Deja et</p>

	<p>al., 2006 (85), Garcia Lizana et al., 2003 (48), Gardner and Sibthorpe, 2002 (47), Griffiths and Jones, 1999 (49), Griffiths and Jones, 2001 (50), Hayes et al., 2000 (54), Hurel et al., 1997 (57), Jacobs et al., 1988 (86), Jones et al., 1994 (87), Maddox et al., 2001 (58), Moran et al., 2005 (59), Mundt et al., 1989 (60), Russell, 1996 (62), Snowdon et al., 1995 (63), Walling, 2006 (65), Young et al., 2005 (88)</p> <p>2. Information booklets from critical care units and websites</p> <p>3. Websites:</p> <p>http://www.icusteps.org/, http://www.i-canuk.com/default.aspx,</p> <p>http://www.ics.ac.uk/patients_relatives/patients_relatives_section,</p> <p>http://www.ardsusa.org/index.htm</p>
<p>Specific changes in activities and role</p> <p>functioning experienced by critical</p> <p>care survivors (although most of the</p> <p>information in this domain/dimension</p> <p>was derived from the qualitative</p> <p>interview data)</p>	<p>1. Selected references from scientific literature:</p> <p>Angus and Carlet, 2004 (3), Boyle et al., 2004 (36), Brooks et al., 1997 (37), Capuzzo et al., 1996 (39), Capuzzo et al., 2000 (40), Chaboyer and Grace, 2003 (41), Daffurn et al., 1994 (44), Garcia Lizana et al., 2003 (48), Gardner and Sibthorpe, 2002 (47), Gordon et al., 2004 (79), Griffiths and Jones, 1999 (49), Griffiths and Jones, 2001 (50), Hayes et al., 2000 (54), Hopkins and Jackson, 2006 (80), Hurel et al., 1997 (57), Jacobs et al., 1988 (86), Mundt et al., 1989 (60), Parno et al., 1984 (89)</p> <p>2. Information booklets from critical care units and websites.</p> <p>3. Websites:</p> <p>http://www.icusteps.org/, http://www.ardsusa.org/index.htm</p>

Having reviewed the contribution of the literature to the preliminary conceptual framework, the next section presents the content of the preliminary conceptual framework.

2.3. Preliminary conceptual framework for HRQoL of critical care survivors

The framework consisted of six broad domains/dimensions that were likely to be affected after critical care and thus, could potentially influence the HRQoL of survivors. These domains/dimensions were: physical; emotional/psychological; cognitive; spiritual; social¹⁰; and activities and role functioning. The details of the preliminary framework are set out in Table 2.2 below. This framework was the appendix to the topic guide for the in-depth face-to-face interviews undertaken in this study (see Chapter 3, Section 3.2 for more details of these interviews) and served as an aid (general questions and prompts) for me to structure and steer the interviews whenever necessary.

Table 2.2: Preliminary conceptual framework for HRQoL in critical care survivors

Possible dimensions/domains for HRQoL of critical care survivors
<ul style="list-style-type: none">Physical.<ul style="list-style-type: none">Mobility/exercise tolerance (muscle weakness).Muscle dysfunction in other areas such as swallowing and cough.Fatigue.Numbness/paraesthesia (neuropathy/nerve palsies).Itching/pruritus.Balance.Pain/stiffness.Communication/speech (long term tracheostomy).Appetite/nutrition.Sleep.Sexual functioning.Specific organ dysfunction such as breathlessness or need for long-term organ support such as dialysis.Cosmetic concerns (alopecia, tracheostomy scars, scars from invasive monitoring, etc).

¹⁰ Place of residence and finances were included under the social aspect of HRQoL alongside with elements such as relationships and support that are traditionally classified under this heading, as they did not comfortably fit into any other domain/dimension identified by the literature review.

- Psychological.
 - Anxiety/panic attacks.
 - Depression.
 - Guilt about putting family through the experience.
 - Anger and conflict within family.
 - Nightmares.
 - Post-traumatic stress (flashbacks, anxiety/panic attacks, traumatic memories of critical care, etc).
 - Amnesia of events/loss of time causing stress.
 - Moving on, looking into future.
- Cognitive.
 - Memory.
 - Concentration.
- Spiritual
 - Outlook in life.
 - Support from spirituality/church.
- Social
 - Relationships with family and friends including any changes in how survivors relate to others and how others relate to survivors.
 - Support from family and friends, medical/nursing/auxiliary staff, work (degree of dependency).
 - Social integration and whether they feel isolated from their social networks.
 - Living arrangements/residence.
 - Finances.
- Activities and role functioning.
 - Ability to look after themselves.
 - Getting around, including getting to the toilet, etc.
 - Washing/showering.
 - Personal grooming.
 - Dressing.
 - Eating and drinking.
 - Ability to run their own lives.
 - Shopping.

- Handling money.
- Preparing meals.
- Driving.
- Work.

2.4. Conclusion

This chapter reviewed the preparatory phase of the qualitative interviews conducted in this study. It discussed how the preliminary conceptual framework for survivors' HRQoL was constructed and presented the content of the framework. This framework outlined some of the issues that might arise from the data. In addition, it formed the appendix to the topic guide used for the in-depth face-to-face interviews undertaken in this study, where it was used to loosely guide and structure the interviews when necessary.

The next chapter explores these qualitative interviews in more detail, including how the topic guide (and appendix) was used in the study. It also describes the study population and presents a brief overview of what constitutes HRQoL for survivors based on the data collected during these interviews.

Chapter 3: Qualitative interview methods and study participants

3.1. Introduction

One of the main aims of the study was to gain an understanding of and define the concept of HRQoL from the perspective of critical care survivors. In order to do so, in-depth face-to-face interviews were conducted with a group of survivors to elicit their views on the important changes that had occurred and/or were occurring, particularly in relation to the impact of critical illness on them and their lives.

The first part of this chapter focuses on the methods employed during the interview process, including the recruitment and sampling strategies undertaken for these interviews. This is then followed by a description of the study population and a brief overview of what is important to these study participants in terms of the concept of HRQoL. The chapter concludes with a summary of how the thesis would report the detailed findings on what constitutes HRQoL from the perspective of critical care survivors.

3.2. Qualitative interview methods

In-depth, face-to-face interviews with critical care survivors were the mainstay of data collection in this study. The study sought to obtain survivors' views on what they perceived to be important in terms of the consequences of critical illness (to understand how survivors see the concept of HRQoL), and the current recommended practice with regard to seeking such insights is to start with qualitative research methods (17). As stated by Ritchie et al., the use of these methods to increase one's understanding of the subject matter is appropriate when the phenomena being studied possess any of the following characteristics: poorly defined; deeply rooted; complex; specialist; intangible; or sensitive (90). HRQoL undoubtedly displays some, if not all of these qualities (17).

The interviews were conducted with ethics approval from the Stockport Research Ethics Committee (REC reference number: 07/H1012/55, date of approval: 19th September 2007) and the London School of Hygiene and Tropical Medicine Ethics Committee (application number: 5201, date of approval: 18th October 2007). Local research and development governance approval was also given at the study sites involved in the study.

The rest of the section discusses:

1. The sampling strategy used to select the study participants to be interviewed;
2. The identification of potential participants and their recruitment; and finally
3. The structure and format of the interviews conducted with study participants.

3.2.1. Sampling strategy

A systematic but non-probabilistic sampling strategy was used to select the study population (17, 90, 91). Such a strategy did not aim for statistical representation in the study population but selected participants deliberately on the basis that they possessed particular characteristics that might affect how they defined their HRQoL (17, 90, 91). Other than symbolic representation, such sampling also ensured that the sample chosen was as diverse as possible within the boundaries of the defined population (90). Diversity was required for two reasons. Firstly, it maximised the chances of identifying the full range of features contributing or influencing the HRQoL of critical care survivors (90). Secondly, it allowed the interdependency between different characteristics to be studied so that those most relevant could be disentangled from those which had less impact (90).

In this research, a combination approach to sampling was used. In the initial stages, individuals were selected such that there was as much variation between their ages, ethnicity, admission diagnoses and lengths of stay in critical care as possible, on the grounds that the literature review (conducted for the development of the preliminary conceptual framework for HRQoL of critical care survivors) and the interviews from the Health Experiences Research Group indicated that these factors were likely to have affected their post-discharge experience. For the same reason, some attention was also paid to gender to ensure that there was not a substantial bias towards either sex. The participants recruited at that point were all between six and twelve months after discharge. This was to allow for recovery time without significantly compromising the recall of relevant information; the participants were sampled such that there was maximum variation between six to twelve months after their discharge from the critical care unit.

After the first ten participants had been interviewed, another method of sampling was introduced into the sampling strategy in that the data were examined carefully (initial analysis) and the findings were then used to guide further sampling. Such a sampling method utilised the principle underlying theoretical sampling. Like theoretical sampling, the findings of a preliminary analysis were used to help guide sampling so that emerging themes/theories could be refined (90). However, the data were not analysed thoroughly immediately after each interview with the findings of the analysis guiding the selection of the next case. Therefore, the sampling strategy could not, strictly speaking, be termed theoretical sampling. Rather, this study could only claim to have utilised the principle underlying theoretical sampling.

On reviewing the preliminary analysis with the selection criteria, there were no obvious selection criteria that needed to be changed or added.

However, on a practical level, there were two problems when using these criteria to recruit participants. First, after reviewing what had occurred thus far in the study with the process of recruiting and arranging interviews, it became apparent that some participants were becoming ineligible by the time their interviews could take place¹¹. At the point of review, this had occurred with two of the survivors recruited for the study.

Second, after further discussion with the two clinicians involved in identifying and recruiting the participants, it became clear that survivors who were non-white in terms of their ethnicity, survivors who had been admitted electively and survivors who had had very short stays were very difficult to recruit. In terms of recruiting survivors who were non-white, the difficulty lies in the fact that both study sites served a predominantly white population. With respect to the latter two groups of survivors, they were not usually invited back to the critical care follow-up clinic¹²(where recruitment was taking place¹³), because they were less prone to problems (92-97). In fact, even when these survivors were invited for follow-up, they were inclined not to attend, again because they generally had fewer problems to report. This, coupled with the fact that critical care clinicians tended to have no contact with survivors after discharge from critical care, other than in the follow-up clinic, meant that practically, these patients were virtually impossible to recruit.

Therefore, the research protocol was altered to recruiting participants between six to fifteen months post critical care discharge at the time of their interviews. In addition, the following two restrictions were introduced into the sampling strategy:

1. Only White British survivors would be recruited and;
2. Only survivors who were emergency admissions into the critical care unit would be looked at (with as much variation in the admission diagnoses as possible).

In terms of length of stay, every effort continued to be made to ensure that patients

¹¹ The patients who were recruited very close to the end point of twelve months post discharge were very often not interviewed in time because of the time that needed to be given to them for their consideration of the study and also because of their other commitments.

¹² In terms of length of stay, both clinics generally only followed up survivors who had a stay of five days and above with one clinic inviting back patients who had shorter lengths of stay but were not being followed up by any other specialty (this did not happen often).

¹³ After discussion with the ethics committee approving this study, it was felt that recruiting through the critical care follow-up service was the best way forward, and therefore, this strategy was adopted for the study.

with widely varying lengths of stay were recruited.

Sampling of participants and data collection continued with the (modified) selection criteria until no new themes emerged from the data (the point of 'data saturation'). In this study, the point of 'data saturation' occurred after twenty-five participants had been interviewed.

3.2.2. Recruitment strategy

Participants were originally recruited from one critical care unit, at Wythenshawe Hospital, Manchester. This unit was chosen because the patients admitted to this unit were representative of the critical care population in England. In addition, it had a large throughput, which would help with patient recruitment. Unfortunately, in the initial period of the study, the critical care follow-up clinic in Wythenshawe Hospital, Manchester, through which all patients were recruited, was still in the process of becoming established, and therefore, patient recruitment was slow.

Consequently, a second site, the critical care unit at Whiston Hospital, Liverpool, was approached to participate in the study too. Like the unit in Wythenshawe Hospital, Manchester, its patients were representative of the critical care population and it had a large throughput. It also had the advantage of having the most established critical care follow-up service in the United Kingdom.

In the end, the numbers recruited from these two units were roughly equal; Wythenshawe Hospital, Manchester, recruited 12 patients while Whiston Hospital, Liverpool, recruited 13 patients.

The clinicians from both units helped identify survivors fitting the sampling criteria and approached them about the study. They outlined the purpose of the study to them¹⁴ and obtained verbal consent from the survivors to be contacted. Details of the survivors who consented to be contacted were then forwarded to me to make the initial telephone contact. During the initial contact, the study was explained to them in detail and they were given at least 24 hours to think about participating in the study. They were then re-contacted by telephone to check whether they were still willing to participate, and if they were, a convenient time to interview them was arranged. All the interviews in the study were carried out in the homes of the

¹⁴ The letter of invitation and the information sheet used in the study are in Appendix B.

survivors, and written consent¹⁵ was obtained in their homes just before the interviews were formally started. At each stage, the participants were told that they could withdraw at any point of the study.

3.2.3. Structure and format of interviews

As already stated, in-depth face-to-face interviews were the main method of data collection in this study. These interviews were conducted with survivors, mainly on a one to one basis, by me. Three out of the twenty-five interviews were conducted with a relative present because of circumstances¹⁶.

Two different face-to-face strategies were employed to collect data about these survivors' HRQoL:

1. An in-depth semi-structured interview based on a topic guide¹⁷. This topic guide focused specifically on consequences of critical illness that survivors regarded as important for their QoL and the ways they assessed these consequences; and
2. A 'questerview'¹⁸, a form of cognitive debriefing. In this case, an expert consensus generic HRQoL measure for this population (that is, either the SF-36 or the EQ-5D¹⁹) served as a focus to trigger narratives and generate data relating to individuals' perceptions and definitions of HRQoL and its assessment. The 'questerview' also provided insight into how well each measure captured aspects of HRQoL in this population group.

During the in-depth interviews, the topic guide was used to cover the following broad subjects: (i) survivors' personal status and the condition of their lives after their illness; (ii) survivors' personal status and the limitations they had suffered

¹⁵ The consent form used in the study is in Appendix B. The consent form included specific consent for a letter to be sent to participants' GPs. This letter has also been included in Appendix B.

¹⁶ Two of the relatives concerned were spouses. The reason participant 03's husband remained in the room where the interview was held was most probably because there was nowhere else in the house he could go to comfortably throughout the interview. For participant 22's wife, she appeared to crave the social contact and company. The remaining relative was participant 04's brother who turned up to visit him in the middle of the interview and joined the interview midway.

¹⁷ The topic guide used right at the start of the study is in Appendix C. There were some small changes made to the wording of the topic guide as the study progressed to help participants understand better what was being asked of them. The broad subjects covered by the questions remained unchanged.

¹⁸ A term coined by Adamson et al. to describe the use of standard measures within in-depth interviews 1. Adamson J, Gooberman-Hill R, Woolhead G, Donovan J. 'Questerviews': using questionnaires in qualitative interviews as a method of integrating qualitative and quantitative health services research. *Journal of Health Services Research and Policy*. 2004 Jul;9(3):139-45.

¹⁹ The SF-36 and EQ-5D questionnaires are in Appendix C.

from before their illness; and (iii) brief details about critical illness, such as reason for admission, length of stay in critical care, length of hospital stay and length of time since critical care and hospital discharge. If necessary, the appendix of the topic guide (the preliminary conceptual framework of survivors' HRQoL) was used as general questions and prompts.

The topic guide struck a balance between having an agenda useful in steering the discussion and incorporating adequate flexibility in the wording and ordering of the topics to allow for the pursuit of issues of particular relevance to individual participants in greater detail (17, 90, 91). In addition, when participants spontaneously mentioned issues/aspects which were not explicitly stated in the topic guide, these unanticipated issues/aspects of HRQoL were followed up (17, 90, 91). The data generated from this part of the interview were used to hone the preliminary conceptual framework to yield a finalised, patient-based conceptual framework for HRQoL of critical care survivors.

The 'questerview' component of the interview involved participants being asked to complete either the SF-36 or the EQ-5D followed by a qualitative interview using the questions from either instrument and participants' responses to these questions as the basis of the interview. This component fulfilled three purposes. First, the survey questions served as a form of topic guide. They acted as trigger questions to draw out narratives about survivors' HRQoL and how they interpreted and assessed it. Such narratives helped to supplement the data that had already been collected (during the previous in-depth semi-structured interview) on the domains/dimensions contributing to survivors' HRQoL and the items suitable for measuring it. This in turn served as a way of further fine-tuning the patient-based conceptual framework.

Second, during the 'questerview', the survivors were prompted to discuss whether they had any concerns that were not covered in the SF-36 and the EQ-5D, and if so, what these concerns were. They were also encouraged to focus on whether the different items used to measure each dimension/domain were appropriate to them. These data further clarified the changes/issues/domains that were important to survivors in terms of their HRQoL and helped establish the extent to which the SF-36 and EQ-5D captured these changes/issues/domains.

Finally, asking participants to complete the HRQoL measures helped elicit the cognitive processes employed by participants when completing these instruments. Participants gave feedback on their comprehension and interpretation of the questions and the associated response categories and instructions. They also provided insights

into the process they went through to produce the answers, by verbalising aspects such as how they made their judgments and decisions about response categories. All this helped identify questions and response categories that were problematic to these survivors and foster an understanding on how to assess HRQoL in this population group.

The in-depth interview was always conducted first followed by the 'questerview'. This was to ensure, as far as possible, that the participants spoke freely about what truly mattered to them when it came to their day to day life without any interference from the content of the two questionnaires. Whilst conducting the 'questerview' first could have helped participants gain some insight into what the study was looking at and thus, increased the richness and relevance of the data collected during the in-depth interview, there was always the possibility that introducing the HRQoL measures at that very early stage could result in participants having preconceptions about what kind of data was being looked for in the study. Given that the study was designed to increase the understanding of what HRQoL meant to survivors, the possibility of this kind of interference occurring would have gone against the primary aim of the study. Therefore, despite the fact that conducting the 'questerview' first might have improved the data obtained during the in-depth interview, it was felt that obtaining naturalistic data was paramount and thus, the in-depth interview was always conducted first.

The last point to note in this subsection was a practical issue. Before the study started, there was the worry that the interviews might be too challenging for the patients to complete in one session and that the two components of the interview might have to be conducted separately at different times. In general, this was not a problem.

However, many of the participants involved in the study had a lot to say. The total interview time for the twenty-five participants was close to forty hours. Although the shortest interview lasted only twenty-eight minutes, the longest interview took five hours (conducted over two separate sittings) with a significant number of interviews taking between one and a half to two hours to complete. Thus, for three of the study participants (participants 12, 13 and 22), their interviews could not be completed in a single session. For all three of them, their first interview lasted well over an hour before they were too tired to continue. Their interviews, therefore, had to be completed on a separate occasion.

3.2.4. Data analysis

The qualitative interviews generated vast amounts of data. Before effective analysis could be carried out, the data had to be prepared. The interviews were all audio-taped digitally and these recordings were transcribed to provide a written record. The interviews were all transcribed semi-verbatim by a professional team of transcribers. Everything that the participants said was transcribed, including the pauses, as well as ums, ers and repetitions. Where emotions were obvious (like being tearful), these emotions were conveyed in brackets. However, the lengths of the pauses were not transcribed and some of what I, the interviewer, said was paraphrased. Each transcript was transcribed as soon as possible after its completion and the transcript was checked by me and amended where necessary. Annotations that would help with the interpretation of the transcribed interviews and thus, the analysis were also added to the transcripts at this point. For instance, sometimes, the participants made gestures during their interviews to help demonstrate their point, or to indicate something. The transcribers were not present during the interviews, and clearly could not pick such gestures up just by listening to the recordings. This was when annotations were made in the transcripts after they were completed.

The analytical process occurred in parallel with the data collection so that its results could inform the sampling of further participants. The findings were also used to help modify the in-depth interview topic guide where required, allowing hypotheses to be developed and emerging avenues of inquiry to be pursued. For instance, it became apparent that survivors often needed prompting to speak about cognitive changes. Quite a few survivors had noticed that they had cognitive changes since their critical illness, but did not make the connection between their cognitive changes and their critical illness. Consequently, they did not realise that it was relevant to the study and they did not think to speak about it unless prompted. Although there was always the possibility that the prompts could result in participants being directed as to what to say, there was no evidence from the study that it was happening among the participants taking part. The affected participants, when agreeing to the prompts that cognitive changes could be a problem, were able to elaborate further and give concrete examples of how the cognitive changes had significantly affected their lives. Furthermore, there were also instances when participants responded negatively to the prompt relating to whether they had any cognitive issues, indicating that participants did not simply acquiesce to what was being said.

Thematic analysis was undertaken with the interviews (98-100). The analysis of the 'questerview' component was slightly more complicated in that the data was used to answer three separate questions and therefore, analysed accordingly. The first question to be answered was similar to that addressed in the semi-structured topic guide interview; to identify the different domains/dimensions that affect the HRQoL of survivors, including their relative importance and also how to measure them. The second was whether the SF-36 and EQ-5D did cover all the relevant domains/dimensions, and if not, the domains/dimensions they did not cover. This indicated the extent to which these measures were capturing important aspects of survivors' HRQoL. The third and last goal was to investigate whether the way the items were asked and/or how the response categories were organised were open to misinterpretation, and if they were, how they introduced sources of error, thereby threatening the validity of the data.

Even before data collection through the qualitative interviews started, there were already some basic ideas about what was likely to arise from the data, particularly in relation to what constituted HRQoL for survivors. These ideas were obtained from the literature review and the developmental work with the interviews from the Health Experiences Research Group. The preliminary conceptual framework (appendix of topic guide) had been the crystallization of these ideas. As data collection progressed, ideas about the data, including possible codes, were recorded for further reference.

When ten interviews had been conducted, formal coding of the transcribed texts using NVivo 8 began. Although formal coding started at that stage, the codes were still kept fairly fluid so that any emerging patterns from the data could be taken into account. At this point, these codes were also discussed with my main PhD supervisor and a critical care survivor who was also engaged in qualitative research. Once all the data had been coded, analysis was carried out using the 'OSOP' method employed by the Health Experiences Research Group (100). All the issues raised by the data placed under one code were noted on an 'OSOP' ('one sheet of paper') and these were then grouped together into broader themes (a process known as 'axial coding'), according to the process described by Ziebland et al. (100).

Having reviewed the methods used to select, identify and recruit the study participants; the interview procedures; and the analytical process, the next section describes the study population in detail.

3.3. Profile of study participants

The study participants consisted of twenty-five critical care survivors. In the process of recruiting these twenty-five study participants using the recruitment procedures described earlier in the chapter, twenty-nine potential participants²⁰ were contacted. Two of these participants became ineligible for the study by the time their interviews could take place. One patient subsequently declined to be interviewed, while one patient was not ready to be interviewed at the time she was contacted (she asked to be contacted at a later date). The patient who declined to be interviewed said that she had returned to normal and was back at work. She felt that she could not make time to do the interview. The other patient appeared willing to take part, but was too traumatized by the whole experience surrounding her critical illness to contemplate talking about it at that point. She was awaiting therapy to help her come to terms with the experience and wanted to have gone through that before revisiting the memories. She asked me to re-contact her at a later date should more patients be needed and she would reassess the situation then. As the study had managed to recruit and interview all the required patients before the date she asked to be re-contacted, she was not approached again.

The rest of this section describes the study participants in detail. The demographics of the study population are covered first before the details of their critical illness are presented.

3.3.1. Demographic profile

Of the twenty-five study participants, eleven were males and fourteen were females. They were aged between 25 to 76 years old with the following age distribution: two in the age range 21-30; five in the age range 31-40; four in the age range of 41-50; four in the age range of 51-60; four in the age range of 61-70; and six in the age range of 71-80. In terms of ethnicity, they were all White British (consequent to the sampling decision outlined in Section 3.2.1). With regard to marital status, seven were single, thirteen were married or with long term partners, one was separated, two were divorced and two were widowed (although one had a new partner). Nineteen out of the twenty-five survivors had children, with the number of

²⁰ These twenty-nine participants all agreed to be contacted for the study and formed part of a bigger group who was approached to take part. Some patients were approached but refused to take part in the study. Their details were not released to me as they had already refused to take part. In addition, the study did not collect any information about why they refused to participate. Therefore, it was not possible to ascertain exactly what kind of patients would refuse to take part in such a study and whether there was a consistent trend seen.

children ranging from one to five.

At the time of interview, the survivors had varying employment status. Twelve were retired, two of whom had retired because of their episode of critical illness. The remaining ten had retired before their critical illness, out of whom two had retired for medical reasons²¹. Of the remaining thirteen survivors, eight were not working while five were working at the time of their interviews. Of the survivors not working, two were unemployed prior to their critical illness. One went back to work, but was made redundant and was, therefore, unemployed at the time of the interview. The remaining five had not been able to go back to work. Four of them indicated that they would have to get different jobs due to some of the residual problems that they were facing after their illness. As for the survivors who had gone back to work, two of them were doing white collar jobs while the other three had blue collar jobs. At the time of interview, they appeared to be working at their previous level although three of them had had to be phased back into work initially. The remaining two survivors had not had this initial period of lighter duties, but only one admitted to having struggled with his work duties at first.

In terms of housing and living arrangements, there was also a degree of heterogeneity among the survivors. Twenty-two of the survivors were living in houses (all with stairs) with the remaining three living in flats (two with stairs inside the flat and one with stairs within the block of flats). It should be noted that one of the survivors had to go to a nursing home after hospital discharge for about four months because she had been unable to return to her original residence and had had to wait for a house with modifications to become available.

As for living arrangements, seven lived alone²². Twelve lived with their spouse/partner out of whom four had their children and one had a grandchild living with them. Four (all females) lived only with their children although one of them occasionally had her partner staying over. With regard to the remaining two survivors, one was staying with his parents while the other was staying with a friend.

These details are summarised in Table 3.1.

²¹ One has been admitted to critical care because of these medical reasons, while the critical illness of the second survivor seemed unrelated to his pre-existing medical conditions.

²² One had a girlfriend who occasionally stayed over.

Table 3.1: Demographics of study population (n=25)

Sex	
Male	11
Female	14
Age (in years)	
21-30	2
31-40	5
41-50	4
51-60	4
61-70	4
71-80	6
Ethnicity	
White British	25
Other ethnic groups	0
Marital status	
Single	7
Married/with long term partners	13
Separated	1
Divorced	2
Widowed	2
Children	
Have children	19
No children	6
Employment status	
Retired	12
Retired prior to illness	2
Retired because of critical illness	10
Not working	8
Unemployed	3
Unable to work	5
Working	5
Type of job held by those who worked	
White collar job	2
Blue collar job	3

Type of housing	
House (with stairs)	22
Flat	3
Living arrangements	
Living alone	7
Living with others	18
Living with another adult (+/- children)	14
Living only with children	4

3.3.2. Details about critical illness

Critical care units look after patients whose conditions are life threatening but potentially recoverable with constant close monitoring and support from invasive equipment and medication (101, 102). Reasons for admission to critical care are very varied. In general, patients are admitted either as planned admissions after major surgery or as emergency admissions as a result of an acute illness (102-104).

This study focused on survivors who were admitted to critical care as emergencies²³. Ten were surgical emergencies²⁴. These include two cases of trauma (one, a road traffic accident and the other a bomb injury), one case of perforated ulcer, one case of gastrointestinal bleeding, three cases of pancreatitis, one case of sepsis secondary to an infected hernia sac, one case of strangulated femoral hernia, and one case of peritonitis.

The remaining fifteen cases were medical emergencies²⁵. Two of these survivors had medical complications after elective surgery while the rest had conditions that were generally managed medically without surgical intervention. With regard to the two survivors who had had medical complications after surgery, one was admitted for bowel surgery for ulcerative colitis. After surgery, he unfortunately contracted pneumonia followed by multi-organ failure necessitating critical care. The other survivor had a hip replacement complicated by post-operative myocardial infarctions and *Clostridium Difficile* diarrhoea.

Regarding the remaining thirteen survivors, their diagnoses included

²³ The reason for this was explained earlier in the chapter, in Section 3.2.1.

²⁴ Defined as emergencies that needed surgical intervention or had the potential to need surgery.

²⁵ Defined as emergencies that needed medical intervention but in general did not need surgery.

pneumonia with or without adult respiratory distress syndrome (four cases), status epilepticus with asthma (one case), sepsis (three cases; one was due to pyelonephritis, one had sepsis with her chest as the suspected source and one suffered overwhelming sepsis due to meningococcal septicaemia), drug overdose resulting in hepatorenal failure (one case), adverse drug reaction (one case of cocaine and ecstasy intake resulting in adult respiratory distress syndrome and seizures), pneumococcal meningitis (one case) and Guillain-Barre syndrome (two cases).

With such heterogeneity in the critical care population, it is hardly surprising that the lengths of stay in both critical care and hospital varied considerably. However, despite all efforts at recruitment, survivors with short stays (less than seventy-two hours) could not be recruited. Consequently, for survivors in the study, length of stay in critical care ranged from three to sixty-three days. As for the length of stay in hospital, it was anything from two and a half weeks to nine months. Survivors were all interviewed between six and fifteen months after critical care discharge and between three and fourteen months after hospital discharge.

These details are tabulated in Table 3.2.

Table 3.2: Details on critical illness

Type of emergency	
Surgical	10
Trauma	2
Perforated ulcer	1
GI bleed	1
Pancreatitis	3
Sepsis (related to surgery and surgery required)	1
Peritonitis	1
Strangulated femoral hernia	1
Medical	15
Complications after surgery	2
Pneumonia (+/-ARDS ²⁶)	4
Status epilepticus and asthma	1
Sepsis (medical causes and no surgery required)	3

²⁶ Acute respiratory distress syndrome.

Drug overdose	1
Adverse drug reaction	1
Pneumococcal meningitis	1
Guillain-Barre syndrome	2
Length of stay in critical care	3 days to 63 days
Length of stay in hospital	2 and a half weeks to nine months
Length of time since critical care discharge	6-15 months
Length of time since hospital discharge	3-14 months

3.3.3. Individual profiles of study participants

Table 3.3 gives the individual profile of each study participant.

Table 3.3: Individual profiles of study participants

Participant	Age	Sex	Admission diagnosis	Length of stay in critical care	Length of time since critical care discharge	Length of stay in hospital	Length of time since hospital discharge
01	72	F	Road traffic accident	49 days	7 months	24 weeks	3 months
02	30	M	Bomb injury	28 days	10 months	36 weeks	5 months
03	73	F	Perforated ulcer	42 days	12 months	12 weeks	10 months
04	54	M	Gastrointestinal bleed	11 days	9 months	8 weeks	8 months
05	56	M	Pneumonia	26 days	9 months	5-6 weeks	8 months
06	34	M	Pneumonia and ARDS	28 days	8 months	8 weeks	7 months
07	62	F	Pancreatitis	17 days	7 months	4 weeks	7 months
08	36	F	Aspiration pneumonia secondary to hypoglycaemia	42 days	6 months	7 weeks	5 months

Participant	Age	Sex	Admission diagnosis	Length of stay in critical care	Length of time since care discharge	Length of stay in hospital	Length of time since hospital discharge
09	72	M	Myocardial infarction and <i>Clostridium Difficile</i> diarrhoea after hip replacement	14 days	7 months	7 weeks	6 months
10	66	F	Pancreatitis due to gallstones	36 days	7 months	12 weeks	5 months
11	44	F	Status epilepticus and asthma	10 days	7 months	3 weeks	7 months
12	53	F	Sepsis due to infected hernia sac	3 days	15 months	3 weeks	14 months
13	46	M	Pancreatitis	36 days	12 months	7 weeks	11 months
14	71	F	Strangulated femoral hernia	49 days	7 months	16 weeks	5 months

Participant	Age	Sex	Admission diagnosis	Length of stay in critical care	Length of time since critical care discharge	Length of stay in hospital	Length of time since hospital discharge
15	68	M	Pneumonia after bowel surgery for ulcerative colitis	7 days	14 months	4 weeks	13 months
16	40	F	Peritonitis	4 days	15 months	3 weeks	14 months
17	73	F	Sepsis due to pyelonephritis	13 days	9 months	4 weeks	9 months
18	34	M	Overdose leading to hepatorenal failure	14 days	14 months	4 weeks	13 months
19	44	F	Septicaemia leading to marked skin scarring and bilateral amputations	35 days	8 months	22 weeks	4 months

Participant	Age	Sex	Admission diagnosis	Length of stay in critical care	Length of time since care discharge	Length of stay in hospital	Length of time since hospital discharge
20	25	M	ARDS and seizures secondary to cocaine and ecstasy	43 days	12 months	9 weeks	11 months
21	76	M	Pneumococcal meningitis	10 days	6 months	6 weeks	5 months
22	66	M	Guillain-Barre syndrome	63 days	13 months	13 weeks	12 months
23	52	F	Sepsis	14 days	8 months	8 weeks	7 months
24	31	F	Pneumonia with atrial septal defect	17 days	8 months	2 and a half weeks	8 months
25	41	F	Guillain-Barre syndrome	40 days	12 months	7 weeks	12 months

This concludes the detailed description of the study population. The next section gives a brief summary of what matters to survivors when it comes to their HRQoL, which also highlights some of the difficulties involved in researching such a subject. The chapter then concludes with an overview on how the detailed findings on this subject would be presented in the thesis.

3.4. An overview of what constitutes HRQoL for critical care survivors

An episode of critical illness was clearly life changing for most of the study participants, many of whom had a lot to say about the changes that had occurred/were occurring in their lives after their illness. As already stated earlier, the interview time for the twenty-five participants totaled close to forty hours, with the shortest lasting about twenty-eight minutes and the longest, about five hours (conducted on two separate occasions).

It was evident that the following changes after critical illness mattered to study participants when it came to their QoL: changes in the various aspects of their personal status; and the consequences brought about by these changes in their personal status. The changes in personal status that were of importance to the interviewed survivors were physical changes, emotional/psychological changes and cognitive changes. Correspondingly, survivors described how these physical, emotional/psychological and cognitive changes affected their lives. These effects extended to many areas of their lives and consequently had a significant impact on their QoL.

It should be said that the exercise of identifying what constitutes HRQoL in the critical care population is, on the one hand, incredibly complex because of its heterogeneity on many levels. First, the personal status of every survivor before their episode of critical illness is unique (3). Second, critical illness is precipitated by a wide variety of events and diseases (3). Third, individuals' reactions to these events and diseases are unique to themselves, as is their capacity to recover (3). In short, critical illness is not a specific disease, but a unifying description for life-threatening processes (2, 3). Consequently, individual survivors can have very different illness and recovery trajectories with distinctive impairment and disability profiles (3).

On the other hand, critical illness, regardless of precipitating cause, is a generalised and severe event which exerts extreme stress on all the organs of the human body (3). Therefore, certain events and processes are almost universal among these patients (3). Examples include a hypermetabolic state, use of invasive monitoring, the need for organ support of some form, frequent use of medication to

keep patients unconscious and a period of immobility (3). As a result, there are certain shared experiences and transitions among survivors.

Survivors of critical illness share the common experience of coming extremely close to death as they survive a life-threatening illness. Yet they can differ from one another in many ways. Therefore, the analytical and presentational challenge lies in accurately representing the viewpoint of these survivors (a diverse group of individuals who have been through a similar experience) without the representation getting overly unwieldy.

3.5. Conclusion

The next three chapters report the detailed findings on the various aspects of survivors' personal status, and the impact each aspect of survivors' personal status exerts. These findings are presented in the following order:

- Chapter 4: Survivors' physical status and the impact of this status.
- Chapter 5: Survivors' emotional/psychological status and the impact of this status.
- Chapter 6: Survivors' cognitive status and the impact of this status.

These chapters are then followed by a chapter (Chapter 7: The role of contextual and personal factors) that focuses on the effects of contextual and personal factors. This is because the interview data indicate that although the changes described by study participants as affecting their HRQoL arose after critical illness, many of these changes were not just due to the critical illness alone; instead, they were the product of the critical illness as well as the context survivors had been/were in. Moreover, the data also demonstrate that personal factors affect survivors' perception of the aforementioned changes, which, in turn, help determine how these changes influence their HRQoL.

Chapter 4: Survivors’ physical status and its impact

4.1. Introduction

In this chapter, I focus on the changes in survivors’ physical status, and the impact these changes had. The first part of the chapter describes the physical changes experienced by survivors while the second part of the chapter delineates the impact of survivors’ physical status on their lives.

4.2. Description of survivors’ physical status

There was considerable variation in physical status among the survivors interviewed, with huge diversity in the kind of physical changes experienced. This is because the resultant physical status of each survivor is contingent on a variety of factors that tend to differ across survivors. These factors include: a person’s physical status before his/her illness; the features of the disease or precipitating cause underlying the illness; the characteristics of concurrent disease(s); the consequences of subjecting the body to the severe strain of being critically ill and the treatment processes of critical care; the medical interventions that he/she has had or is having; the physical resilience of that particular individual (that is, an individual’s intrinsic capacity to recover from severe physical disability (3)); and finally, the stage of recovery the individual is at.

The study has attempted to reflect the reality of the heterogeneity of the critical care population in as accurate a fashion as possible, and consequently, the list of physical changes raised by survivors participating in this study is fairly long. This is summarised in Table 4.1.

Table 4.1: Physical changes experienced by survivors of physical illness

- Fatigue.
- Weakness which can affect all muscle groups.
- Sensory problems, including:
 - Pain.
 - Numbness.
 - Hearing problems.
 - Poor eyesight.
 - Poor awareness of body positioning and movement.
 - Abnormal sensations, such as increased itching.
- Balance issues.
- Poor coordination, with both gross and fine movements.

- Tremor and other abnormal movements.
- Decreased joint mobility.
- Changes in a person's physical form, including physical deformities.
- Shortness of breath.
- Chronic cough.
- Loss of appetite.
- Altered taste perception.
- Difficulty swallowing.
- Nausea and vomiting.
- Weight fluctuations (weight loss or weight gain beyond weight before illness).
- Stomas.
- Hernias.
- Problems with defecation control, particularly in patients with stomas.
- Urinary incontinence.
- Impaired sexual functions.
- Skin, hair, nail and teeth changes.
- Wounds and scars.
- Increased sweating.
- Loss of voice.
- Stammer.
- Side effects of medications (which can also include any of the problems listed above).

This list may not be exhaustive²⁷, especially when applied to every single individual who has ever survived an episode of critical illness, but it probably covers the majority of the more common physical changes experienced by survivors. It also serves to demonstrate the breadth of physical changes that can arise in this population group.

Given the large number of physical changes raised by study participants, it is not practical to explore each physical change in detail, but it is worth noting some general points about these changes:

²⁷ It has already been stated that survivors can differ considerably from one another on an individual level. Therefore, although the study has tried to ensure, as much as possible, that there is a maximum variation within the characteristics that would affect how survivors view their HRQoL, there is no guarantee that this list would cover every single physical change experienced by every single individual that has survived an episode of critical illness.

- The physical changes described by study participants were often not consequent to their critical illness alone but rather, they were due to both the critical illness and contextual factors. For example, for participants 19 and 25, pain was a problem for them after their critical illness, but it was controlled to some extent by their medication. As a result, the pain that they were describing during their interviews was more a product of both their critical illness and the medication that they were taking (contextual factors), rather than that of the critical illness alone. The part played by contextual factors is discussed further, in detail, in Chapter 7, but it is essential to be cognizant of the fact that many of the physical changes highlighted by study participants were, in reality, reflective of both the critical illness and the context these participants had been/were in, rather than just the critical illness itself.
- In general, survivors perceived all the physical changes described negatively. Nonetheless, there were still instances when survivors viewed some of these changes as positive ones. For instance, participant 16 welcomed the marked weight loss that was fairly common after critical illness, because she had wanted to lose the weight. As a matter of fact, her critical illness was triggered by a gastric band insertion going wrong.
- The frequency at which each physical change occurred in this population varied. Some were more or less universal complaints, like marked fatigue and weakness. Other changes such as increased sweating or loss of voice were far less common.
- Some of the physical changes, such as pain, were fluctuating in nature.
- Different physical changes could be interrelated. For instance, having a stoma meant that a person no longer had any control over when he/she defecated; decreased joint mobility might result in a change in one's physical form; muscle weakness could contribute to unsteadiness; loss of appetite might be due to altered taste perception; while fatigue and sensory problems could cause a degree of impaired coordination. These are but a few of the examples of this interdependence between different physical changes.
- Some changes such as fatigue and weakness tended to resolve while other changes such as poor coordination and balance might persist for a long time. One could not say definitively with these study participants, that some survivors would be left with residual problems, as the study participants furthest along their road of recovery were only fifteen months after critical care

discharge and there was evidence to indicate that complete recovery could sometimes take years (71, 92). However, some study participants did talk about effects that seemed to have become chronic. For instance, participant 25 spoke about the fact that there had been no improvement in her pain level for some time. Therefore, it would not be inconceivable if some survivors never recovered completely from a physical point of view.

4.3. Impact of physical status

According to the participants interviewed, their physical status had a wide-ranging impact with implications for their QoL. These effects can be broadly classified into the areas outlined in Table 4.2.

Table 4.2: Areas that could be affected by a survivor’s physical status²⁸

<ul style="list-style-type: none"> • Physical appearance. • Activities and behaviours: <ul style="list-style-type: none"> – Posture and mobility. <ul style="list-style-type: none"> ▪ Personal posture and mobility. ▪ Using transportation. ▪ Driving. – Sleep/rest. – Communication. – Self-care activities. – Activities associated with societal roles. – Other activities. <ul style="list-style-type: none"> ▪ Recreational and leisure activities. ▪ Social activities. ▪ Sexual activity. • Physical zone of activity. • Suitability and availability of clothes. • Interactions and relationships with others. • Place of residence. • Finances.
--

²⁸ Some of the labels used for the areas may not be as well defined/self evident as others. When that is the case, a precise definition would be given so that the reader is clear on what the thesis is referring to. Such definitions would apply throughout the entire thesis.

- Other aspects of personal status.
 - Emotional/psychological consequences.
 - Cognitive consequences.

Before exploring each of these areas in more detail, there are a few general points to make. First, the effects being described often did not stem simply from survivors' physical status after critical illness. Rather, they were the result of the interplay between survivors' physical status after critical illness and the context they were/had been in. For instance, whether a survivor could return to their original place of residence after their illness is not only dependent on their physical status after but also on contextual factors such as their original housing and living arrangements, including the presence/absence of support at home.

A concrete illustration of this point is seen in participants 02's and 22's cases. Participant 02 had made a remarkable recovery given the nature of his illness (traumatic bomb injury). In his words, "basically because I was so active, I am frustrated that I can't do certain things. Like I always used to go for a run or go out on the bike and things like that...because I can't bend my left knee at the time it's like I can't get down to dry my lower left leg or my left foot so that's the help that I need really. My mum and dad help me with that, just drying the leg and putting the sock on and tying my shoe but everything else I can do type thing. I don't have any problems with everything else so I think that's the major thing really.". Besides needing some help with certain self-care activities, he was mainly just restricted in strenuous physical exercise/activity. However, he had worked and lived overseas prior to his critical illness and these physical restrictions, while comparatively not as limiting as those seen in some other survivors, meant that he could not return to his original place of residence.

In contrast, participant 22 was physically so disabled that he could not even turn himself over in bed when he first left the hospital. However, he was able to return home to where he had previously lived with a lot of support from his wife, and after some structural modifications of his home. Looking at these two cases, it is clear that the resultant impact of an individual's physical status was contingent on the contextual factors of their lives.

As already stated, the role these contextual factors play is specifically discussed in depth in Chapter 7, but it is important to be conscious of their modulating

effects when examining the impact of survivors' personal status on their lives, or in this case, more specifically, the impact of survivors' physical status on their lives. To help this, whenever it is clear from survivors' narratives that contextual factors have a role to play, it would be highlighted.

Second, when discussing the impact of survivors' physical status in relation to their QoL, the aim had been to be as comprehensive as possible. Therefore, each of the areas in Table 4.2 influenced the QoL of at least some of the survivors within the study population at any given time. However, that was not to say that they would affect the QoL of all the survivors to the same degree at any given time²⁹. Different survivors perceived the same change differently³⁰. For instance, the change in appearance caused by a stoma seemed very important in influencing participant 12's QoL, but it appeared to have minimal impact on the QoL of participant 14. Furthermore, survivors often experienced changes in perceptions as they adapted to life after critical illness, so that the changes they had experienced and/or were experiencing after their illness affected their QoL in different ways at different time points. For example, participant 14 became used to her limitations in activities and behaviours, and these limitations did not appear to have an impact on her QoL at the time of her interview. As she said, "...if I go out with my daughter to the Trafford Centre, now, normally we'd go two or three times a year, and we'd go early in the morning, say about half nine and we'd have our lunch, we'd traipse around and it might be 6 o'clock when I'd be getting back home, where now, it has to be half past ten, eleven and I'm coming back at half three or four, but that's not a hardship, is it? I don't even notice I'm not doing as much, I just get tired in that shorter distance, shorter time. I just do to my capabilities. So it's not worrying me. It's not upsetting me.". For the sake of comprehensiveness, all effects described by the study population had to be included, but including them also resulted in a degree of irrelevance for certain survivors, either from the outset or with the passage of time. The inherent tension between comprehensiveness and relevance is further discussed in some depth in Chapter 9. However, it is worth remembering that not everything explored in the ensuing discussion on the impact of survivors' physical status would be relevant for all study participants and indeed, for all critical care survivors at all time points,

²⁹ In fact, some of these areas might even have zero effect on certain survivors' HRQoL at that point in time.

³⁰ This perception is heavily influenced by the inherent characteristics of individuals (namely, personal factors). There would be more in-depth discussion on the role personal factors play in affecting HRQoL later on in the thesis, in Chapter 7.

especially after the process of adaptation has been factored in.

The third point relates to the second; survivors differed from one another in terms of how they described and delineated the various areas listed in Table 4.2 and also, individual survivors sometimes changed their precise definition of these various areas over time as they adapted to their situation. The differences and/or changes in survivors' description of areas (and sub-areas) were especially pertinent to the very broad area 'activities and behaviours'. To give an example of how different survivors often delineated the various areas of their lives differently, the sub-area 'personal posture and mobility' included running for participants 02 and 18 whereas it stopped at walking and climbing stairs for many other participants. This variation between survivors was even more striking when it came to sub-areas such as 'activities associated with societal roles', 'recreational and leisure activities' and 'social activities'. This was because such sub-areas were affected by individuals' demographics³¹, choices³² and perceptions³³, all of which could vary considerably between survivors. With regard to individual survivors changing how they delineate various areas over time, participant 14's case would, again, be a good illustration of the point. Before her illness, her definition of the sub-area 'personal posture and mobility' definitely included climbing stairs. After her illness, as she adapted to her limitations, climbing stairs was not as crucial in her definition of that particular sub-area as it was before, because she avoided climbing stairs whenever she could. Again, the aim had been to be comprehensive, so the descriptions of the areas (and sub-areas) took into account the interview data from the entire study population, with the boundaries of these areas (and sub-areas) defined by data from survivors with the broadest delineation of the areas (and sub-areas).

Finally, although the effects have been divided into the areas (and sub-areas) listed in Table 4.2 for ease of discussion, the reality was much less neat; a given consequence in one area could have knock-on effects on other areas. For instance, for participant 13, a change in physical appearance resulted in cosmetic concerns and

³¹ As an example, participant 01, who was a 72 year old grandmother, mother and wife spoke about cooking, shopping, cleaning and looking after grandchildren when talking about domestic activities and chores. In contrast, participant 02, a 30 year old single man who spent the majority of his time overseas, had completely different domestic activities when he stayed with his parents on the occasions he came home. He used to help his dad with building work.

³² For participant 22, DIY, reading and painting were his recreational and leisure activities of choice, whereas participant 02 preferred to engage in sports and physical exercise.

³³ For instance, DIY projects might be viewed as part of domestic chores and activities by some survivors (such as participants 02, 09 and 10) but others (such as participants 05 and 22) enjoyed doing such jobs and regarded them more as a hobby and recreational activity.

increased self-consciousness (emotional/psychological change). Consequently he would not go swimming with his sons (change in activities and behaviours). To prevent the discussion from becoming overly complicated, the specific links between the different areas are not explored in detail, but it is important to remain mindful that these interrelationships exist.

Now that the general points have been covered, the effects in each of these areas (and sub-areas) are explored in more detail.

4.3.1. Physical appearance

Many of the physical changes listed in Table 4.1 could alter the external appearance of survivors. Some such as skin, hair and nail changes were usually temporary but others like scars and stomas might be more permanent. Furthermore, certain changes in appearance, such as hair loss, were more readily apparent to others, whereas issues such as stomas and certain scars could be hidden from view and thus, only obvious to the survivor himself/herself.

4.3.2. Activities and behaviours

A. Types of activities and behaviours affected

Unsurprisingly, survivors' activities and behaviours were affected by their physical status. The activities and behaviours affected could be classified into the following sub-areas:

- Posture and mobility.
 - Personal posture and mobility.
 - Using transport.
 - Driving
- Sleep/rest.
- Communication.
- Self-care.
- Activities associated with societal roles (such as domestic chores and activities, including activities performed to assist others, and paid work).
- Other activities.
 - Recreational and leisure activities.
 - Social activities.
 - Sexual activity.

There is a degree of overlap between the two sub-areas 'recreational and leisure activities' and 'social activities'. Some recreational and leisure activities such as going shopping can also be considered to be social activities when done with

friends. The converse is also true; meeting up with friends for lunch is a social activity, which can also be viewed as a recreational and leisure activity. However, because there are recreational and leisure activities which are not social activities (such as reading) and also social activities, such as attending weddings, which are not necessarily seen as recreational and leisure activities, these two sub-areas have been left separate.

In terms of how the area 'activities and behaviours' has been affected by survivors' physical status, survivors spoke in terms of restrictions in the vast majority of cases. Survivors were either unable to carry out a particular activity, or they were not able to do it in the same way as they had done before their illness. In cases where survivors were restricted by their physical status, no matter which sub-area the activities belonged to, the precise impact of survivors being unable or less able to do a certain activity is often reduced by the appropriate contextual factors such as aids, structural adaptations and support from others. For instance, participant 01 was able to get up stairs with a stair lift while participant 08 was able to go back to work because efforts were made to compensate for her reduced physical capacity.

Whilst restrictions are far more common in this area, there are also occasions when survivors spoke about having to do too much of a certain activity, like having to sleep more or having to engage in more self-care activities like taking medication. To be clear, the type of change is highlighted in the appropriate sub-area.

Each of these sub-areas is now examined in turn.

1. Posture and mobility

This sub-area relates to the posture and movement of the human body, as well as mobility both in and outside the home. Survivors were generally restricted when it came to the category of 'posture and mobility'. These restrictions were in:

- Personal posture and mobility (that is posture and mobility of survivors' own body). This can be further subdivided into:
 - Maintaining a constant sitting/standing posture.
 - Keeping one's upper limbs in a particular position.
 - Moving one's upper limbs.
 - Manual handling activities of the upper limbs.
 - Hand grip.
 - Hand dexterity.
 - Bending/stooping.
 - Transfer activities and postural changes.

- Kneeling/bending knees.
- Walking.
- Getting up and down stairs.
- Running.
- Using transport.
- Driving (this includes driving a car, riding a bike etc).

In some cases, the limitations were reduced by contextual factors. For example, participant 07 and 08 could get up stairs with the help of banisters. In participant 01's case, where she was even more limited, she got up and down the stairs with a stair lift that was installed after her illness.

For most of the activities in this sub-area of 'posture and mobility', the restriction was simply about whether survivors were able to carry out the task in question and in some cases, how long/far they could sustain the performance for.

However, for certain activities, the constraint(s) could be more complex. For example, regarding walking, study participants did not merely talk about whether they could walk and the distance they could walk. They were also concerned about how fast they could walk, whether they could walk with a normal gait, whether they suffered from recurrent falls and whether they could move around without walking into objects. As an illustration, participant 02, despite being able to walk quite a distance, was dissatisfied with his walking because he was walking on his toes. He also spoke about how frustrated he was with the fact that his progress towards walking normally was negated every time he was admitted to hospital for further treatment. As he said, "I do a lot of walking and I'll go out with the dog and the horses...I'll go out with friends or if I go shopping, when I was on my crutches I was tired when I come back but I'd been out for two or three hours...the frustrating thing for me is the Achilles is like concrete...my foot is slightly raised because the Achilles is that tight that it won't go down until I've done a lot of exercise on it. So when I get up in the morning I tend to be on my toes until I stretch and I have a slight heel raising so that's frustrating because I'll get to a level where she's [participant's physiotherapist] really pleased with me and my foot's pretty much down to the ground and then I'll go in for an operation, yet I still do the exercises in there and with the physios but I'm going backwards again...".

Interview data from survivors with more than one kind of walking restriction also support the fact that a limitation in distance is not the only walking restriction of importance to survivors. Participant 08, when speaking about getting her life back to

where it was, was not only interested in being able to walk further. She was also concerned about being able to walk with her foot on the ground and being able to walk without losing her balance. This was what she said during her interview, “I topple over, quite easily...when I went to mum and dad’s a couple of weeks ago, mum and dad have got like a cobbled path around their garden which is all different heights and everything and mum had to grab hold of me because I’d have just fallen...I’ve got nerve damage, I’ve got peripheral neuropathy in my legs, which I had before I was in ICU, but my balance and my stability was a lot better. It wasn’t a problem at all, you know, I could walk for miles and I wouldn’t lose my balance whereas now I do seem to lose my balance...but my doctor has referred me and I’m going to go and get some more physio to try and strengthen up my centre of gravity to try and get my balance back... I said to mum and dad “No, I want to go home, I want to live back by myself again and I want to go back to work and I want to get my life back where it was before” and although it’s probably 90% there, I’ve still got 10%...The 10% is getting stronger with walking, being able to walk further. I get very tired very quickly, my legs go funny. Getting my foot down in the morning and just getting fit again, because I’m not very fit...”. Similarly, participants 10 and 13, in addition to expressing their dissatisfaction about not being able to walk as far, spoke about their inability to walk as quickly as they were able to before their critical illness.

Getting up and down stairs is another activity where it is not just about whether one is able to make it up and down stairs. Many survivors could get up the stairs in their house, even early in their recovery phase, but they were unable to do it in a way they perceived as normal (what is perceived as normal for survivors differed fairly widely). Some needed aids. Others climbed up on all fours or went up and down stairs on their bottoms. Recurrent falls were also an issue in some cases.

Besides noting that there are a number of types of restrictions that survivors could experience when it comes to ‘posture and mobility’, it is also worth emphasising that the pattern of resumption of the various activities of ‘posture and mobility’ was not totally predictable. Although in general, survivors were more likely to resume activities that required less physical capacity sooner, this did not always happen. For instance, both participants 03 and 05 were able to walk at the time of their interviews; in fact, participant 03 made a point of how far she could walk. However, both of them still had trouble with hand grip, an activity which seemingly required less physical effort compared to walking.

II. Sleep/rest

Survivors generally struggled with marked fatigue that was most pronounced right at the beginning of the recovery process, improving as survivors got better. Consequently, survivors ended up sleeping/resting a lot more, especially in the initial period after hospital discharge. Sleeping/resting might be all some survivors did when they first returned home as demonstrated by this excerpt, "...initially everything had to be done for me. A** [participant's wife] would get me up out of bed in the mornings, bring me downstairs, sit me in that chair there...I would sleep at night for about twelve hours. That went on for quite a while...I would sleep for twelve hours and I would doze several times during the day in the chair and still go upstairs and sleep for twelve hours."

For the survivors who would sleep during the day, some were tired enough to sleep at night despite having slept in the day while others were unable to sleep at night, thus disrupting their normal sleep cycle.

III. Communication

Some physical changes could interfere with survivors' ability to speak and hence communicate with others. One participant in this study had no voice for some months after his critical illness. He and his wife had to rely on non-verbal forms of communication. In addition, his wife learnt how to lip read.

Although this physical inability to communicate occurred in only one study participant (out of the twenty-five), it was incredibly frustrating for him, and had quite an impact on his QoL. An example of this is clearly shown by the following excerpt from his interview, "...we've not really come into contact with many people. To be honest with you, we try to avoid it, especially at first, because I couldn't talk for a start. So, the odd friend that we did bump into I couldn't converse with them anyway so everything was done through S** [participant's wife] And more often than not it was, they were talking like as though I wasn't there, or as if I'd lost my marbles. So, they were ignoring me and saying to S** [participant's wife], "We'll come and see him, we'll come and visit." Like on a third person, instead of talking to me, and saying, "P*** [participant himself], how are you? I'll come and see you in a few days' time." Which they never did by the way, it was small talk. So, they'd say to S** [participant's wife], "Tell him I'll come." Well, don't tell S** [participant's wife], tell me. But I couldn't say it because of ((whispers)). I would say ((whispers)). So, for that reason if we went shopping, we went shopping out of town." As evident from the extract, he was upset enough about the consequences of not being able to

communicate effectively that they were part of the reason he and his wife took measures to avoid the people they knew.

IV. Self-care activities

Self-care activities refer to the tasks that a person carries out to take care of his/her personal needs. The following types of self-care activities were affected by the physical changes sustained by critical care survivors:

- Washing oneself (bathing, showering, drying, etc).
- Caring for body parts (brushing teeth, shaving, grooming etc).
- Dressing.
- Toileting (includes voluntary control of urinary and faecal discharge as well as the process of using the toilet).
- Feeding oneself, eating and drinking.
- Looking after one's health (taking medication, going for medical appointments, engaging in physical exercise and sports³⁴, not indulging in health risking behaviour such as smoking and drinking excessive alcohol, etc).

Generally, survivors were physically unable or less able to carry out their self-care activities after their illness; they often needed external help to accomplish these tasks. For instance, participant 10 needed some bathing aids to be able to wash independently.

However, at times, survivors had to increase certain activities relating to looking after their own health, like taking medication or attending medical appointments, consequent to their physical status. Having to do so was regarded as undesirable, as seen in this extract from a survivor's interview, "...I take eight tablets in the morning, then I have to do my blood sugars and have my Warfarin. Then at dinner time, when I have my dinner, I have to take two Creon. And then at night I have to take whatever dose of Warfarin for that particular day, either five or six; my two Creon, my blood sugars and my diabetes medication. When I went in hospital that was my washbag. My husband brought me the washbag. Now that is full with medication. So I think to myself, "Nothing else, please!"".

V. Activities associated with societal roles

As already stated, the precise activities defining this sub-area differed between

³⁴ Engaging in physical exercise and sports does not just fall under the realm of self-care. For some survivors, it is something they really enjoy doing, and therefore, it can be classified under recreational and leisure activities too.

survivors depending on their individual characteristics and circumstances³⁵. The types of activities affected by survivors' physical status in this sub-area included:

- Domestic chores and activities, including activities performed to assist others.
- Work.

However, from participants' narratives, it would appear that there were some differences in the resumption of these two types of activities. Thus, these two types of activities are discussed in turn, in separate subsections.

a. Domestic chores and activities

Domestic chores and activities include all indoor and outdoor tasks related to or used in the running of a household. For all the survivors in this study, carrying out any kind of domestic task was usually beyond their physical capabilities when they were first discharged from hospital. The chores and activities survivors physically struggled with were very varied. They ranged from small physical tasks such as manipulating a pen, opening jars/Tupperware/bottles, peeling vegetables and operating a lighter to more vigorous, manual jobs like lifting building slabs, changing a tire and carrying heavy shopping.

As survivors' physical status improved, they slowly resumed performing the usual chores and activities that they had carried out previously. For participants involved in this study, the extent to which they had resumed their domestic chores and activities varied from one another. On the one hand, some participants were doing all the chores and activities they had been doing prior to their critical illness by the time they were interviewed. On the other hand, a significant number of study participants still had considerable problems performing certain specific chores at the time of their interviews, where their difficulties reflected the residual physical limitations that they suffered from. However, even in those survivors who had resumed all their normal chores and activities, some small degree of restriction usually still existed. They were often unable to complete the chores with as much ease as previously (needing more time or effort). In some cases, they also felt fatigued after finishing everything they would normally have done before their critical illness.

³⁵ For example, for participant 07 who had retired from her job as a nursing sister, the main activities associated with her societal role were domestic chores and activities, which included looking after her grandchildren. For participant 08, a young single female who was employed by a school, this category comprised not only of her domestic chores and activities, but also her work. In addition, even if the two individuals share the same broad subgroup of activity associated with their societal roles, the precise tasks defining the broad activity may also differ. For instance, for one person, his/her domestic chores and activities may be gardening and DIY while for another person, it may be cooking, shopping and cleaning.

In general, unsurprisingly, survivors struggled more with chores and activities that required more physical effort and took longer to resume those activities.

However, some survivors might have specific physical problems that could result in them having trouble with seemingly minor physical tasks even after they had regained the ability to do comparatively more physical chores. For instance, participant 03 was able to push a hover, but was unable to grip and open a jar. Similarly, participant 05 could push a garage door up to open it, but struggled to peel potatoes and grip a spanner. Therefore, in the sub-area of 'domestic chores and activities', the degree of difficulty survivors had with a particular task was not always proportional to the amount of physical effort it took to accomplish the chore.

Besides physical recovery, contextual factors such as aids and structural adaptations could help survivors' resume their chores and activities. For instance, participant 05 could not light the stove with a cigarette lighter, the lighter he had been using before his illness, but he could do so with a barbecue lighter.

b. Work

Work refers to the activities done in exchange for payment. Survivors, if they had been working before their illness, were generally unable to return work activities for a significant period of time because of their physical status. In fact, as some study participants pointed out, they might never return to work after their illness. For example, participant 01 had taken the route of retirement. This is in keeping with the current findings in the literature (45, 47).

For the survivors who had resumed (or would resume) working, returning to work was often not straightforward, as demonstrated by the narratives of many study participants. Some survivors would have to change their jobs, or at least some aspects, should they choose to resume some form of work; their physical restrictions after their illness meant that they were no longer able to carry out the work duties they had been performing before their illness³⁶.

³⁶ The physical limitations which result in survivors being unable to return to their old job is usually imposed by the disease or precipitating cause underlying the critical illness rather than a direct consequence of being critically ill. After all, when a patient is labelled as being critically ill, it is normally because they need constant medical support to keep their organs and body functions going. When a patient recovers from that state of being critically ill, they do suffer from some physical changes/deficits, but in general, these are temporary (other than structural abnormalities like scars, but even these fade). The physical manifestations of the underlying disease or the precipitating cause of the critical illness tend to be more long lasting. However, this differentiation is sometimes not that clear cut. In addition, survivors tend to see it as a change occurring after their critical illness, and attribute it as such, rather than make a clear distinction between the two.

For the survivors who had been able to return to their old jobs, a phased return and/or concessions at work were often necessary, as most survivors were physically unable to do all of their previous work activities immediately on return to work. Fatigue during and after work could also be a significant problem for survivors. Therefore, even when survivors were back at work, it did not necessarily mean that they were back to normal in terms of their working lives.

From the narratives, some degree of physical recovery is clearly important in enabling survivors' to return to work. In some cases, study participants regained their physical status to the extent that they were able to perform physically demanding jobs such as building scaffolding and driving a forklift.

However, there was also evidence in the data to indicate that besides physical recovery, contextual factors played a significant role in whether survivors went back to work. It would seem that survivors were more likely to return to the workforce if their original jobs had been less taxing physically. Of those who had resumed their work, some of them had been able to work despite significant physical restrictions because they had been in jobs that were physically less challenging (white collar versus blue collar). The converse was also true. While the survivors who had not been able to return to work had residual physical limitations prohibiting them from working, at least part of the reason they had been unable to go back to work was because their jobs were physically fairly challenging (even if they were not, strictly speaking, blue collar jobs). This is supported by the fact that some of them were preparing to return to the workforce by seeking employment that would place fewer physical demands on them. As participant 02 said during his interview, "...that was a physical job, obviously doing close protection/body guarding, was in and out the vehicle, all around and everything, so with regards to that, now I'm limited like that...I'll never go back to that job now because there'll be stuff that I can't do...I am going working for myself, after this...that's working with delinquent children like 12 to 16...it's still a physical job if you look at it because you're walking around, teaching and getting involved but obviously the friends who I'm doing it, there'll be aspects that I can't do, which they'll do then...".

In addition, it might be easier to take up employment again if one was able to do the same job as before the illness. Of those who had resumed working (six of the study population), all but one indicated that they had returned to their old jobs. With the remaining survivor who had resumed working, it was not possible to ascertain from his narrative whether he was doing what he has been doing before his illness or

not. However, whatever the case, it would appear that being able to do the same work as before made it more likely that survivors would return to work.

From the above discussion, it is clear that contextual factors played an important part in determining whether survivors resumed work, but such factors could have an even more crucial role in situations where survivors chose to return to work when they were not ready to do so. Within the study sample, there were participants who went back to work without being physically able to carry out all their work activities, either because they needed the social contact or because their financial situation had left them with no choice. The former was seen in participant 08's case while the latter was demonstrated by participant 25's situation. The following extract from participant 25's interview clearly illustrates the point that although she was physically not ready to return to work, she had to do so for financial reasons.

Extract from participant 25's interview:

"I just work Wednesday, Thursday, Friday. I had to go back after six months. Was nowhere near ready. It was ridiculous, but financially was under half pay. And although people say, "Oh, there's benefits." Yeah, but benefits don't take into consideration that you've got car loans and credit cards to pay off, so I had to go back. But work was really good because they did an eight-week sliding return...I was supposed to be going back to year two which is a year group I was unfamiliar with...But then she moved me back to year one so it was a familiar year group, so it wasn't all brand new. And then the lady that I originally job-shared with, her job-share had been off on long-term sickness leave – the new one that they'd employed had been on long-term sickness leave – so I went back to job-share with her. And she's so organised and she's done year two for years and all the planning's in place. So although I find it absolutely shattering and don't want to do it, and spend ridiculous amount of time dreaming up ways how I can have time off work again, it is a lot easier because she does an awful lot of the work."

As also clearly demonstrated by the above excerpt, contextual factors such as the willingness of employers and colleagues to implement special arrangements in the workplace had a pivotal role to play in survivors being able to return to work under the circumstances when they were physically not ready to.

Therefore, all in all, physical recovery was important in the resumption of work. However, it was the recovery comparative to what is required to work that is

important, rather than the absolute level of recovery. In addition, contextual factors such as the responses of employers and colleagues and whether a new job was required were also important in determining whether survivors returned to work.

VI. Other activities

a. Recreational and leisure activities

Recreational and leisure activities are the activities that a person chooses to do for relaxation, pleasure and enjoyment. Unlike activities such as self-care activities, essential domestic chores and activities and work, these are not compulsory activities.

In some cases, because survivors' poor physical status prevented them from carrying out many of their other usual activities, they ended up engaging in more recreational and leisure activities after their critical illness than before their illness. As participant 05 aptly put it, "I watch a lot of telly now because I can't do that much else so television is important...".

However, for many survivors, the physical changes they experienced after their illness had the opposite effect; the changes prevented them from effectively engaging in their usual recreational and leisure activities. The range of recreational and leisure activities affected was very wide, from sedentary pursuits such as reading and solving puzzles to more active undertakings like gardening, DIY projects as well as sports and physical exercise. The fact that even the more sedentary activities were affected was a reflection of how physically disabled some survivors could be after their critical illness.

As evident from the above examples of affected recreational and leisure activities, these activities could vary considerably in terms of the physical demands they placed on survivors. Therefore, whether survivors could resume these activities, and the timing of their resumption were also fairly variable. It was dependent on whether survivors had recovered to the physical level needed to perform the recreational and leisure activities they used to engage in before their illness. In addition, as in the case with activities associated with societal roles, the less physically taxing survivors' recreational and leisure activities had been before their illness, the quicker survivors were able to re-engage in them; for the extremely challenging recreational and leisure activities such as those enjoyed by participant 02 (examples given by him included cycling, running, training in the gym and rugby), returning to them could be extremely delayed with the possibility that it might never happen in some cases.

In certain cases, contextual factors helped survivors resume their recreational

and leisure activities, just like they helped survivors return to their activities associated with societal roles. For instance, participant 22 could perform the essential parts of his DIY projects and gardening when his wife helped him do some of the preparation work like gathering his tools and the materials he needed. As his wife said, " We've had fences, chairs, everything made in this living room. We put dust sheets down, he doesn't make a mess, but things like this, he'll make something like this [a cover to go over the filter that is in the pond in the garden], but I more or less have to get everything for him. So this has sort of like been made from scratch. He's got it together...So if we decide we're going to do a gardening day, I ask him what he wants. I get everything for him, right? Now in the beginning his tool box, which is kept under there, I used to have to get that, but now as long as I take the top one off he says, "I can do the rest." So again, whatever he says he can do, I leave him, but obviously there are quite a few obstacles to worry about in the garden, you know, the grass and stones and slippiness and that. So if he says he's going to do some re-potting I just bring everything for him. He sits there and I bring everything for him, he does it and I take it all back again. Obviously which I wouldn't have done before..."

In short, when survivors' recreational and leisure activities were restricted by their physical status, their resumption of these activities was dependent on their physical recovery in relation to the physical capacity needed to perform their original recreational and leisure activities. Other contextual factors such as practical support would also help.

b. Social activities

For the study, this sub-area encompasses activities geared towards providing opportunities for people to interact with one another or pursuits one does with others. Examples of the former are family gatherings, meetings with friends and special social occasions such as weddings. The latter include recreational and leisure activities like going shopping with family/friends, participating in club activities and going dancing. Although activities such as certain domestic chores and working at a job provide opportunities to interact socially with others (these activities provide the main route of social integration for some survivors), they are not traditionally regarded as social activities and are therefore not included in the analysis for this subsection.

The levels of social activities (as defined above) differed quite significantly between survivors. For some survivors, the amount of social interaction they derived from their day to day interactions with their family and in their work place was sufficient for them. These survivors did not appear to have set much time aside

specifically for social activities. For example, participant 05's main social contact came through his work. His only mention of social activities as defined here was going out for meals with his wife, and a wedding. In contrast, there were survivors who dedicated a significant portion of their time to social activities. Participant 14, whose main social activity was dancing, would go four to five times a week every week.

It must be said, regardless of the level of social activities before a person's critical illness, the poor physical status of survivors, especially early in the recovery process, had a prohibitive effect on their ability to engage in their usual social activities. This was not surprising as many of the social activities that survivors had been engaged in took place outside their homes and most, if not all survivors were not physically well enough to leave their homes initially. Furthermore, many of the social activities survivors talked about required some physical effort, and they were clearly not up to the task from a physical point of view, especially initially.

However, although survivors' physical status did result in a noticeably reduced level of social activity for some, the impact was not as evident for others. First, social activities were modified to better suit the physical status of survivors at that point in time. For instance, before his critical illness, participant 15 used to meet up with his friends during his swimming sessions. During his recovery from critical illness, he was unable to go swimming, but still saw his friends because they would visit him.

Second, interestingly enough, for some survivors, their physical status allowed them to take part in new social activities. This was despite them not being able to participate in the social activities that they would normally have participated in before their illness. For instance, participant 10 was meeting with certain family members and friends more frequently although she was unable to join in all the family gatherings and functions that she would normally have attended. There were two possible reasons for this involvement with new social activities. First of all, an episode of critical illness was often a life-changing event, not only for the survivor, but also for family and friends. As a result, both the survivor and the people around them might end up wanting to get together more often. Secondly, with many survivors limited in the activities they could do, they tended to end up with more free time that they have had previously. This allowed them to dedicate more time to social activities, particularly when these activities were tailored to their physical limitations. These two reasons might also help explain the paradox of survivors participating in new social activities while not being able to resume their previous social activities. The new

social activities often resolved around the survivor and were adapted to their needs. Consequently, it was often easier for survivors to take part in such social activities.

In terms of returning to their previous social activities, again, as in the case with the resumption of other activities and behaviours, survivors resumed their usual social activities when they could manage it. As with the previous two sub-areas of activities, activities which required less physical effort such as visiting friends/family were generally resumed more quickly while survivors took more time to return to activities which were physically more taxing like shopping with friends or going dancing.

c. Sexual activity

A few survivors in the sample suffered from impotence with a resultant fall in their sexual activity. In addition, there were survivors who were reluctant to engage in sexual activity consequent to a change in their physical appearance and increased self-consciousness.

For many of these survivors, they appeared to have had no sexual activity whatsoever since they had been critically ill. One of them had been discharged from the critical care unit for 12 months with no improvement in the situation.

Lack of sexual activity was spoken about less than most other limitations. The exact reason(s) for this is unclear. It might be that the problem was indeed less common among survivors. Alternatively, it might be because it was a sensitive topic and not often talked about openly, especially with a stranger. Most survivors in the study were interviewed on only one occasion and, other than the initial contact over the telephone, they had had no other interactions with me. There was not much time to build rapport to speak about such an intimate topic. For the male survivors, this barrier might have been further compounded by the fact that I am female. Last but not least, it might also be because sexual activity did not contribute significantly to QoL in this population group.

B. Balance of activities and behaviours

With the changes in activities and behaviours discussed above, it is inevitable that there was some shift in the balance of survivors' activities and behaviours. Survivors tended to rest more and engage less in other activities, particularly right at the beginning, when they were first discharged from hospital. As survivors recovered physically, this shift in survivors' activities and behaviours reversed itself.

However, for many survivors, this process of reversal could take a significant period of time (and might end up never fully reversing). As participant 17 said, "Well,

I feel as though like I've gained about 20 years, you know. Most of time since then I've felt like a very old woman, as though I've moved on a generation, you know, almost. I have been quite limited. Particularly things like, any kind of physical activity. I don't whiz round with a vacuum cleaner anymore. I haven't got back to gardening even yet and that used to be my main interest, down the garden. I find that, well it's nine months now isn't it, since I went in. June last year to March, so...I certainly haven't caught up with myself and I've given up expecting to really."

4.3.3. Physical zone of activity

It is evident from the interview data that the physical zone of activity a survivor could cover could be affected by their physical status. Participant 01 was essentially confined to her home, due to the combination of: problems with walking; difficulty getting down steps; and the inability to manoeuvre herself into a car. Participant 05 was marginally better off. He could travel short distances but found it difficult to do so.

While it could be argued that asking about survivors' posture and mobility would give an indication of the area survivors could physically cover, the correspondence between survivors' posture and mobility and their zone of activity was, in reality, not quite so straightforward. For example, participant 10 was very reliant on her wheelchair and as such, appeared less mobile than participants 01 and 05 who could both walk (participant 01 with the help of a zimmer frame while participant 05 could walk on his own at the time of the interview). However, she was able to navigate down her front steps with help and use transport (in her case, she was driven around by her partner), thus allowing her a much greater physical zone of activity (even though someone had to push her wheelchair around when she got to her destination). Therefore, merely asking about survivors' posture and mobility might not give an accurate picture of their physical zone of activity.

4.3.4. Suitability and availability of clothes.

A few of the study participants found that many of the clothes they had worn before their illness were now unsuitable for them. This was a particularly significant issue for the survivors who had a fairly drastic change in their physical form. These survivors could not wear most, if not all, of their clothes after their critical illness.

Given that some of these bodily changes took a long period of time to resolve, having nothing (or almost nothing) to wear was a real problem for some of these survivors. Participants 12 and 17 provided good illustrations of this issue. Participant 12, because of the location and considerable prolapse of her stoma, found that she

could no longer wear any of her clothes, from her underwear right through to her outer clothes. The only clothes she could wear were her pyjamas. As she said, "...when it first happened, that [the stoma] was up here but the hernia's pushed everything down. But to me it's easier to cope with down there. When it was up here, I couldn't wear a bra or anything, I had to get maternity bras and everything because the underwired bra, they hurt, I just couldn't wear them. And I can't wear any of my clothes with zips in the pants. I can't wear a skirt...So it's all your clothes. My underwear, I can't wear any of my normal knickers, I have to get the Sloggi knickers that come right over...for weeks I stayed in pyjamas because it was more comfortable for me but then I wanted to get dressed and I wanted to go out, so we just had to change all my clothes. I've got a wardrobe full of clothes upstairs that I just can't wear. I can't wear anything, I know it sounds silly, but you see the likes of this 'cause you can see through it [referring to the transparency of the garment she had on during the interview], I have to have these [the camisole she was wearing under the transparent garment] under it because otherwise you can see that [the stoma]. All that has been hard to cope with. I found that really hard with my clothes and everything, I found that hard.". Due to the fact that her stoma was not going to be reversed in a reasonable time, her only option was to acquire a whole new wardrobe. However, even doing this was fraught with problems, because her condition was fairly uncommon and there was a paucity of information about suitable clothes for her.

Participant 17, who found all her clothes way too big for her because of substantial weight loss, shared a similar problem. She constantly wore a couple of tops and a pair of stretch pants for quite some time because she was too unwell to go shopping and was not regaining weight fast enough to wear her other clothes.

Although there were also survivors who had to modify what they wore due to their functional limitations in dressing, these survivors did not have as big a problem with regard to the clothes they could wear. This is because these survivors were generally able to wear something out of their wardrobe (compare this to the survivors who, as a result of bodily changes, could not wear most, if not all of their clothes). Furthermore, the unsuitability issue was often a temporary problem because many of the functional limitations tended to improve over time.

4.3.5. Interactions and relationships with others

From the narratives, it is clear that interpersonal interactions and relationships could be affected by survivors' physical changes as well as the consequences of these physical changes. Both the number and nature of the interactions and relationships

could be affected.

A. Changes in number of interactions and relationships

Some survivors ended up engaging in fewer relationships. For instance, participant 22, because of fatigue and also problems communicating, chose to avoid everyone other than his wife and close family. He and his wife even chose to shop outside the area they lived in so that they would not meet people they knew. Furthermore, survivors might also interact less within the relationships they retained. In extreme cases, like participant 19's, even spouses and children, people who were meant to be one's closest and dearest, might be perceived as not being in one's life. Participant 19's husband and children, because she lived in a nursing home (which was in turn due to her physical problems), were only spending about half an hour with her everyday and she felt cut off from them. Due to the combination of fewer relationships as well as decreased interactions within the remaining relationships, survivors could feel socially very isolated.

B. Changes in nature of interactions and relationships

In addition to the quantity of interactions and relationships, the nature of relationships could also be affected in a number of different ways. First of all, survivors described being treated differently by their families and friends as well as the other people they came into contact with. Participant 19's husband treated her like "one of the children" when before her illness, they had had a more equal partnership. If anything, she "won most of the arguments" and had more say. Participant 12 talked about how her husband would not sleep in the same bed as her for about six months because her prolapsed bowels made him fearful that he would accidentally hurt her. Moreover, he and their sons got very protective of her and would stop her from doing what she wanted to do because they were worried about her hurting the bowels which had prolapsed and were outside her body. It was not just people close to the survivors who treated them differently. Even strangers or people whom survivors were occasionally in contact with could do the same. Participant 19 talked about how people stared at her because of her bilateral leg amputations. She, and a few other survivors reliant on wheelchairs, also spoke about how they were ignored or seemingly unseen by the people around them.

Second, survivors were unable to carry out the activities required to fulfill the role they used to play in the lives of others. For example, many of the female survivors in the study used to do most of the cooking and cleaning in the household but were no longer able to do so. On a more intimate level, a few survivors brought up the

issue of not being able to engage in their usual sexual activity with their partner/spouses.

The third change is related to the second; critical care survivors were often more dependent than they had been on the people around them. Participant 08 was reliant on her parents for all self-care and domestic activities when she was first discharged from hospital. Many survivors were in a similar boat. For a number of survivors, this constituted a role reversal. As participant 01 said, "I used to be very sort of independent and, always on the go doing something, but it seems different that way. I feel more useless, you know what I mean? As though, I used to be the one in charge and doing everything for everybody, it's the other way around now."

Finally, conflicts between survivors and those around them might be more prevalent. Participant 19 said that she used to shout at her husband because of the way he treated her (the way he was treating her had changed because of her physical limitations). Similarly, participants 07, 10 and 12 had disagreements with their families/friends because of the responses of their families/friends to their physical limitations.

Another possible reason for increased conflict was the sleep disturbance that could occur in survivors. As participant 10 said, "...basically the first fortnight, three weeks, I could, say, get up about eightish, because I have to have insulin at eight o'clock, and then I'd be asleep by half past nine, ten o'clock. And then he [participant's partner] always used to make sure I was awake for five to have my insulin again, but if I slept in between, he wouldn't wake me up. And then I used to go up about half past nine like I did, but I'd be wide awake, wouldn't I, because I'd had a good sleep. So I'd put the bedside lamp on and read or try to read, you know, or even very nastily some nights, switch the telly on and watch the telly and he'd be trying to sleep. So it was very difficult really..."

Therefore, it is clear that survivors' physical status (and some of the consequences stemming from that) could affect their interactions and relationships with others significantly.

4.3.6. Place of residence

Some study participants (participants 02, 17, 19, 23, 24 and 25) did not return to their original place of residence immediately after their discharge from hospital/rehabilitation facilities. Participant 02 moved in with his parents, participant 19 was discharged to a nursing home to await suitable housing while the remaining four participants stayed with either family members or friends for a variable period of

time before moving home.

While there was some correlation between the severity of survivors' functional limitations and their likelihood of returning to their own home, the situation was usually slightly more complex. This was because whether survivors could return to their original place of residence was also partially dependent on contextual factors such as their previous living arrangements and the presence/absence of support. Participant 02's case has already been given earlier as an example; although he was physically no more limited than many other survivors in the study sample, it was almost inevitable that there would be a change in his place of residence. He had been living overseas for his job. Given the seriousness of his illness, there was no way that he could return to his job and therefore, to his original living arrangements immediately post discharge from hospital.

Likewise, although the other survivors who did not return to where they were living before were all fairly limited physically, there were survivors arguably more physically disabled who returned home. For instance, one survivor was so physically debilitated that he could not turn himself in the bed, but he managed to return home after being discharged from rehabilitation facilities, mainly because he had the support of his wife and also, arrangements such as a ramp were put in place for him at home. Conversely, for survivors who could not return to their original place of residence, the fact that they lived alone or with others who could not provide support (like young children) and the type of housing³⁷ also played a role, alongside their physical status, in their inability to return home.

4.3.7. Finances

A few survivors whose physical status prevented them from working spoke about the impact on their finances. For some survivors, it was not merely their own income that had been affected. Their physical limitations were such that they needed someone at home with them; and hence, someone else in the family (normally the partner/husband) had to stop working too, which further affected their finances.

In addition, some survivors had increased outgoings because of their illness. For example, participant 19 had to move into a rental property with her family because of her physical limitations. This meant that they had to pay rent on top of the mortgage payments they were already making on their house.

³⁷ Participant 19 would have to navigate multiple steps to get to her front door. With her bilateral leg amputations, there was no way she could get up those steps, especially initially in the recovery process. She had since been fitted with prosthetic legs and was undergoing rehabilitation with them at the time of her interview.

Not every survivor who had to stop working or had increased outgoings raised this topic of finances spontaneously. For some, they had other financial support and money did not seem to be a problem. For others, it might be that the state of their finances, whatever that might be, did not significantly affect their QoL. Alternatively, it might not have been brought up not because it was not an issue, but because survivors were not comfortable talking about it.

4.3.8. Other aspects of a survivor's personal status

A. Emotional/psychological consequences

In some survivors, the physical changes as well as the consequences arising from these changes resulted in significant emotional/psychological consequences. Some of the more common emotional/psychological consequences included:

- Frustration/anger. Study participants cited many reasons for their frustration/anger, including the protracted recovery process, their relative dependence on others and their limited physical zone of activity. In addition, some survivors were very displeased at how the people around them tried to restrict them in what they wanted to do. Finally, even the practical support provided in response to survivors' various restrictions could be a source of irritation. For example, participant 07 was using her wheelchair to help her mobility. However, in the end, she got so frustrated using it that she abandoned it and started walking. Another illustration would be participant 19's case. She had to move into a nursing home because she could not physically get up the front stairs of her original home. She mentioned a few times in her interview how frustrated she got while staying there.
- Worry, anxiety and fears. The poor(er) physical status of survivors and its impact on their performance of activities was a powerful trigger of worry, anxiety and fears for many survivors. For instance, participants 07, 08, and 10 all wanted someone to be with them when they were climbing stairs because they were worried that physically, they would not be able to handle the stairs without mishap. Sometimes the anxiety was particularly prominent or only triggered when survivors had to leave their homes, as in participant 13's case. He was anxious about walking outside his home on his own due to fears that his physical problems would make it easier for someone to knock him over. It was not just the decreased performance of activities that could cause worry, anxiety and fears. The other consequences of poor physical status, such as financial concerns, could also spark off such feelings. Participant 12 was one

survivor who was extremely worried about her finances.

- Sadness and depression. With many of the changes already described, it was unsurprising that a number of the critical care survivors in the study felt a sense of loss. This in turn could lead to sadness and depression. For instance, participant 03 felt depressed when she could not do the things she used to be able to do before her critical illness. Participant 19 described down days when she felt sorry for herself because of the loss of her legs and her thumb as well as her resultant functional limitations.
- Cosmetic concerns and body image issues. As already stated, there could be a change in survivors' external appearance. In addition, some of the physical changes could result in survivors encountering problems with the clothes they were able to wear (as discussed under Section 4.3.4: Suitability and availability of clothes). With these changes, cosmetic concerns and body image issues could arise. Participants 03, 16, and 19, who all noticed differences in their hair, were concerned enough to undertake measures to counteract what they perceived to be undesirable changes in their appearance. Participant 12, who had a stoma, said that it was "horrendous and ugly". She tried not to look at herself in the mirror because whenever she caught sight of it, she would think that it was the "most hideous thing" she had ever seen. These cosmetic concerns and body image issues were not limited to women. Participant 13, who had a weight loss of three stones, believed that it made him look emaciated and thus, felt self-conscious and embarrassed. Similarly, participant 02 felt that he no longer looked as good as he had done previously; he spoke about how his injuries meant that he had to wear loose baggy sweaters compared to previously, when he could really dress up and feel proud of how he looked.

B. Cognitive consequences

Survivors' physical status did not seem to directly affect their cognitive status very much. However, one survivor, participant 13, did make the point that his memory was much worse whenever he felt fatigued.

4.4. Conclusion

Critical illness invariably had an adverse impact on survivors' physical status. All survivors interviewed had been severely disabled and required a significant time to recover to their previous physical status. In some survivors, that might never happen. For instance, participant 02 had significant injury to his hip joint with leg shortening.

Although he was still undergoing treatment at the time of his interview, it seemed unlikely that this deficit would be completely rectified. Nevertheless, all the study participants had recovered physically to some degree.

Across study participants, there was some variation in their physical status. Some survivors did not appear to be significantly different from other individuals of the same age and sex and/or what they were like before their illness. Others were still fairly debilitated from a physical point of view. In addition, the precise physical changes experienced by survivors differed considerably from survivor to survivor. This is due to the fact that the resultant physical condition of any individual is contingent on a variety of factors. These include physical status before the illness, the precipitating cause of the illness, the existence of any concurrent disease(s), the body's physical response to the illness and treatment process, the health care interventions the person has had/is having, the ability to recover from the illness and finally, where the individual is in their recovery trajectory.

In terms of the impact of survivors' physical status, these effects were spread over many different areas of their lives. These areas were physical appearance; activities and behaviours; physical zone of activity; suitability and availability of clothes; interactions and relationships with others; place of residence; finances; and finally, other aspects of survivors' personal status. The consequences in these areas, on the whole, affected survivors negatively, although many of these effects could be lessened with appropriate contextual factors.

This concludes the findings on survivors' physical status and the consequences stemming from this aspect of their personal status. The next chapter focuses on their emotional/psychological status and the impact that had on survivors and their QoL.

Chapter 5: Survivors' emotional/psychological status and its impact

5.1. Introduction

This chapter focuses on the emotional/psychological status of survivors as well as the consequences arising from this aspect of survivors' personal status. The chapter first describes the emotional/psychological responses displayed by the survivors before discussing their impact on survivors' lives.

5.2. Description of survivors' emotional/psychological status

The emotional/psychological status of any given survivor after their critical illness is the product of their previous emotional/psychological status, their response to the critical illness experience and the recovery process, the emotional/psychological support they have had/are having, their personal emotional/psychological resilience and finally, the end point of their emotional/psychological recovery or equilibrium (105). Consequently, survivors' resultant emotional/psychological status could differ considerably from one another, from being relatively unaffected and/or unchanged from their previous emotional/psychological status to being completely changed emotionally/psychologically.

In general, if participants had been affected emotionally/psychologically by the critical illness and recovery experience, the overall impact was a negative one; on the whole, survivors tended to be emotionally/psychologically worse off than they had been before their illness. This is hardly surprising as the vast majority of events and changes encountered during the course of an episode of critical illness and recovery are undesirable.

However, although emotional/psychological distress was far more common than positive feelings amongst study participants, positive feelings could still occur at points during the experience. For instance, in response to participant 10's critical illness, her daughter chose to be reconciled with her after years of estrangement, and this had brought participant 10 a lot of joy and happiness. She also talked about how excited she was when she started making progress in her physical recovery. Similarly, participant 08 was very excited when she was able to start driving and working again because for her, it signified "getting her life back".

Besides emotional/psychological changes that were conceded by most to be either positive or negative changes, there were also changes that were not as readily classifiable. A good illustration was provided by participant 10's outlook of being given a second chance in life. On the one hand, it gave her increased motivation to

try new activities. On the other hand, she was also more easily frustrated with her husband because there were times when she perceived that he was wasting precious time that was part of her second chance at life.

All in all, significant emotional/psychological upheaval occurred in many of the study participants and the many different responses are summarised in Table 5.1.

Table 5.1: Emotional/psychological responses of survivors

- Happiness and joy.
- Excitement and enthusiasm.
- Feelings of being lucky and grateful.
- Shock and disbelief.
- Sadness/unhappiness/discontentment/grief reaction and depression.
- Disappointment and feelings of being let down.
- Boredom.
- Anger, irritability and frustration.
- Worry, anxiety/nervousness/panic and phobias.
- More suspicious and distrustful, paranoia.
- Embarrassment/shame/feelings of loss of dignity.
- Guilt and condemnation (“felt like a criminal”).
- Loneliness and isolation.
- Feelings of abandonment.
- Disempowerment, feels defeated and out of control.
- Feelings of confusion and bewilderment.
- Feelings of restriction and confinement (loss of autonomy and freedom).
- Feeling protective of others.
- Feelings of being an outsider.
- Changes in level of interest or motivation (both increased and decreased level of interest/motivation).
- Reduced emotional control (more emotional/tearful, more easily frustrated, etc) with or without mood swings.
- Decreased/lack of (usual) emotional responses, sometimes to the extent of blunted affect/emotional numbness/emotional detachment, which can be both positive (helps coping) and negative (affects relationships).
- Nightmares and dreams.
- Intrusive memories and flashbacks.

- Irrational thoughts, delusions and false beliefs, including delusional memories of critical illness.
- Hallucinations and psychosis.
- Racing thoughts.
- Changes in level of obsessions and ruminations (both a decrease and an increase in obsessions and ruminations).
- Cosmetic concerns and body image issues.
- Lack of libido.
- Poor confidence, low self esteem and increased self-consciousness.
- Recurrence of previous emotional/psychological issues (such as eating disorders or unresolved issues from the past).
- Outlook of being given “a second chance”.
- Increased awareness of mortality.
- Changes/adjustments in general outlook (values, beliefs, attitudes, etc).
- Altered expectations.
- Acceptance of critical illness and recovery experience, including negative changes that have occurred.
- Moving on from critical illness and recovery experience, including planning for the future.

There are a few points of note about these responses. First, as with survivors’ physical changes, the emotional/psychological responses described by study participants were often not just due to their critical illness. Contextual factors such as medication and the presence/absence of psychological support also helped determine these responses. For example, when participant 19 spoke about feeling down on some days, the emotional/psychological status she was describing was the net product of her critical illness and the anti-depressants she had been taking since her critical illness.

Second, the degree (depth as well as breadth) of reaction varied from survivor to survivor. Some survivors were mildly affected. For instance, although participant 09 did feel momentary sadness when talking about what his family went through during critical illness, he asserted that he was, in general, contented and happy with his life. Similarly, participant 07 was specifically anxious about the critical illness happening again, and given that she had no answer as to the cause of her critical illness (she had

had acute severe pancreatitis with no obvious precipitating factor), this response was not entirely unreasonable. Moreover, although she had a degree of anxiety, her anxiety did not appear to have much impact on her life, apart from some reservations about travelling abroad.

Other survivors were more deeply affected, with widespread knock-on effects on their lives. For these survivors, the emotional/psychological turmoil was no longer limited to appropriate responses to the critical illness and recovery experience. They were less able to cope with everyday life and were reacting in a similar way to any perceived stress (related or unrelated to their critical illness). Participants 04 and 25 were examples of survivors thus affected. After his critical illness, participant 04 wrestled extensively with anxiety; although he had had problems with anxiety prior to being critically ill, he conceded that his anxiety escalated after his critical illness. He was due an angiogram in the coming weeks at the time of his interview, and he was so anxious about this angiogram that he was arranging his life around it. He spoke about having to delay sorting out practical support for his day to day life (he wanted help with shopping, etc) and resolving his dissatisfaction concerning his relationship with his mother. He knew that he would risk getting too worked up if he had to deal with these issues alongside his angiogram. It would appear from his interview that he was reacting with anxiety to a lot of the events in his life.

Similarly, participant 25's emotional/psychological problems had significant repercussions for her. She suffered with anxiety after her critical illness and this anxiety, besides being present at times for no obvious reason, was also very easily triggered by day to day events. For example, she had to drive with her car windows down and could only tolerate minimal physical contact with her daughters.

Third, some responses like frustration/anger and anxiety were fairly common amongst the study participants. Other responses such as a deep sense of vilification were spoken about far less frequently. It occurred under very specific circumstances in the one case where a participant had been admitted into critical care because of a suicide attempt and he was being investigated to ascertain that he was emotionally/psychologically well enough to continue working at his current job.

Fourth, there was a degree of interdependence between the various emotional/psychological changes. For example, nightmares and flashbacks could result in stress and anxiety while anxiety could lead to irritability and anger.

Finally, survivors' responses could change over time. As already stated, the emotional/psychological changes were usually negative, much in response to events

and changes as they unfolded. Many of the events and changes associated with critical illness and recovery were temporary and resolved or improved with time (for example, marked muscle weakness alongside the restrictions this placed on survivors tended to get better as they recovered). This removed the stimuli provoking the reactions and restored a degree of equilibrium to survivors' emotional/psychological status. Moreover, even when what was driving the responses continued to be present, many survivors adjusted (reflecting their emotional/psychological resilience) and came to terms with what had happened and/or what was happening. This soothed the emotional/psychological disturbance and helped survivors reach a place of acceptance, which was often a platform for them to look towards the future. This kind of acceptance and getting on with life was clearly described by participant 13 in the following extract; "I've accepted now that I'll never be one hundred percent again but I can do my best, and have a fulfilling life... I've got out of this doom and gloom cycle, because that's how I felt and more acceptance really, accepting I do have to take lots of medication and I do get lots of problems with my legs, but I'm not just going to give up...I'm a real fighter. I mean I've got my bike. It's electrically assisted, but you can use it either electrically assisted, full electric or manual, as a mountain bike. So I go out on that quite often and I've got a rowing machine in my bedroom, I go on that and for next season, I'm going to get back into canoeing...".

On the other hand, some of the stimuli did not settle and/or some survivors were unable to make the adaptations necessary to restore emotional/psychological balance. Therefore, a number of survivors continued to have appreciable emotional/psychological problems with little change over time.

Having examined the emotional/psychological changes experienced by survivors in some depth, the next section explores the effects survivors' emotional/psychological status could have on their lives.

5.3. Impact of survivors' emotional/psychological status

The study participants whose emotional/psychological status had been affected by their critical illness and recovery experience all spoke vividly of how this aspect of their personal status had affected them and their lives. The areas that could potentially be influenced are listed in Table 5.2.

Table 5.2: Areas that could be affected by a survivor's emotional/psychological status³⁸

- Perception of, interpretation of, and responses to life.
- Personality.
- External appearance.
- Activities and behaviours:
 - Posture and mobility.
 - Personal posture and mobility.
 - Using transportation.
 - Driving.
 - Sleep/rest.
 - Communication.
 - Self-care activities.
 - Activities associated with societal roles (includes domestic chores and activities, work and learning activities).
 - Other activities.
 - Recreational and leisure activities.
 - Social activities.
 - Sexual activity.
- Physical zone of comfort and/or activity.
- Interactions and relationships with others.
- Other aspects of the survivors' personal status.
 - Physical consequences.
 - Cognitive consequences.

In Chapter 4, before the effects of survivors' physical status were described in detail, a few general points were made (details in Section 4.3). These points are also applicable here.

To briefly recap, the effects described were often the result of the interaction between survivors' emotional/psychological status and their context (the context they had been in and were in at the time of interview both played a role); they were not

³⁸ The precise definitions for many of these areas and sub-areas have already been given in Chapter 4. The same definitions apply here. When the area (or sub-area) has not been defined in Chapter 4, and it is not evident from the label what that particular area comprises of, the precise definition would be given during the discussion of that area (or sub-area).

consequences arising solely from survivors' emotional/psychological status. The modulating effects of these contextual factors are referred to briefly in the ensuing discussion, but such effects are only discussed in some depth later, in Chapter 7 of the thesis. Second, when discussing the impact of survivors' emotional/psychological status in relation to their QoL, the aim had been to be as comprehensive as possible. This meant that not everything discussed was necessarily applicable to every survivor. In addition, even when a change was applicable, survivors might not be affected to the same degree, and also, they might not perceive it in the same way at all times³⁹. Finally, many of these effects described could have knock-on effects in other areas/sub-areas. To prevent the discussion from becoming overly complex, these interrelationships are not specifically examined in detail. However, it is important to remember that such links exist.

Further, some of the emotional/psychological changes experienced by study participants were consequent to the undesirable changes that had occurred after critical illness and such emotional/psychological changes were often the driving force behind survivors' attempts to reverse the effects of critical illness. For instance, because participant 07 was so displeased about how restricted she was in terms of what she could do that she kept pushing herself to do more, in order to return to what she had been like before her illness. Strictly speaking, such effects resulted from survivors' emotional/psychological status. However, they are not included in the next section describing the details of the impact of survivors' emotional/psychological status. This is because the study is about the changes in survivors' lives in relation to what their lives had been like before their critical illness and whether such changes played a role in affecting their QoL. Therefore, the results presented here have been adjusted accordingly.

The rest of the chapter now focuses on the details of each of the areas and sub-areas listed in Table 5.2.

5.3.1. Perception of, interpretation of, and responses to life

It was clear from the interview data that survivors' emotional/psychological status affected the way they perceived and interpreted their lives (including all their limitations). Participant 13's case illustrated this particularly nicely. He was originally very depressed about all his problems and limitations. Consequently, he did very little

³⁹ Perception stems from inherent characteristics possessed by individual survivors, which would inevitably vary. The role of such characteristics (personal factors) in the concept of HRQoL would be further explored in depth in Chapter 7.

on a day-to-day basis, besides moping around at home. As he said, "I went through a period last year of being just so lethargic, I had no interest in anything whatsoever and I was just living an existence really, up until I would say probably the earlier part of this year but I would get up, at whatever time and I'll come down in my dressing gown and I would just lie on the sofa, just no interest in anything at all and I would just lie there and I'd watch the TV.". Everything looked bleak to him and he found all his limitations very difficult. This view of his restrictions further limited him.

However, as time went on and he started to accept his restrictions, he said the following, "I've accepted now that I'll never be one hundred percent again but I can do my best, and have a fulfilling life...I've got out of this doom and gloom cycle, you know, because that's how I felt and more acceptance really, you know, accepting I do have to take lots of medication and I do get lots of problems with my legs, but I'm not just going to give up...I've got back into fishing, again...I've got a lot of things going on. I've got numerous hobbies and most of the time there aren't enough hours in the day, there really aren't. I mean, I build computers, I repair computers, just for friends, and sometimes I can have five computers in here, all on the go and, and I've got my electronics which I'm into and white noise generators won't interest you at all, so I won't go there and the train set's up in the loft and I do a bit of wood carving and playing the guitar, badly sometimes, you know. Computers, I'm a real geek with computers, you know, all sorts, all sorts. But as I say, it's been a journey to get here.". Although he still had many of the same constraints, it was clear that due to his emotional/psychological status, he did not perceive them in the same way. They did not bother him as much and hence had a far lesser effect on his well being. Consequently, it also increased the range of activities he was engaging in. It was evident from participant 13's narrative that his perception of his limitations contributed directly to his well being, but also indirectly through the activities he was participating in.

Besides affecting how survivors perceived and interpreted life, survivors' emotional/psychological status could also affect how they reacted to life. For some study participants, they had stronger emotional/psychological responses to aspects of life, including to things that had not bothered them before their illness. In the vast majority of cases, the responses involved undesirable emotions like sadness, anxiety/fear and anger. The extent, level and appropriateness of the reactions varied tremendously among the study participants.

At the one end, responses were limited to specific situations with the level of

emotions ranging from mild to severe. Very often, these reactions seemed appropriate or at least understandable given the circumstances. Examples of survivors in whom this occurred were participants 05, 07, 09, 10 and 22. Participants 07, 10 and 22 had been relatively fit and well previously, and climbing up and down stairs had not been something they were worried about before their critical illness. After being seriously ill, having to climb up stairs invoked a degree of anxiety in them because of their poorer physical status and consequently, they all wanted someone with them when climbing stairs.

Participant 05 started watching out for standing pools of water after contracting Legionnaires' pneumonia. He also refused to go swimming despite being told of its benefits for his physical recovery because he was told that Legionella had been discovered in a swimming bath.

In participant 09's case, he was understandably apprehensive about further surgery after an operation that had led to complications and a stay in critical care. He said during his interview that he would not go through another operation. This was despite the fact that he had undergone quite a few surgical procedures in his lifetime. It was clear that his attitude and response towards surgery had altered because of his critical illness.

At the other end of the spectrum were survivors in whom these reactions were more extensive and generalised. Such survivors would frequently react intensely to many aspects of ordinary life, thus making their responses seem very inappropriate. For instance, participant 25 would not go to her hairdresser because of feelings of panic. In fact, she deliberately created an argument with her partner so that she could get out of going to a wedding, all so that she could avoid a visit to the hairdresser. This all stemmed from the belief that nurses had poured water into her mouth while washing her hair in critical care. She clearly stated during her interview that she knew that this was not true and that her phobia was "ridiculous", yet she still would not visit her hairdresser. Her anxiety was not limited to the situation with the hairdresser either. She also could not stand physical closeness of any kind. She had avoided crowded places since her critical care discharge and even hugging her children was a problem for her because the physical contact "turned her stomach" and "made her skin crawl". Participant 24 shared this aversion to physical closeness. Consequently, she would not go shopping or pick her children up from school if she could help it.

Another survivor who experienced marked and inappropriate emotional/psychological responses was participant 11. She had a high level of fear

and anxiety that was fairly global in that it extended to many areas of her daily life. She herself said that she had many “unrealistic fears”, such as being frightened of the rain and the wind. Besides fear and anxiety, anger was another emotion that could be provoked in participant 11 by a seemingly bland stimulus. Her daughter came in wearing a green top midway through our interview. On seeing it, she told me that it made her angry and therefore, she planned to get her daughter to change out of that top when she next saw her. Due to such altered responses to a big chunk of day to day living, she ended up avoiding a wide variety of things. For example, she would not go out, ride in a vehicle or go to hospital for follow-up appointments if she could help it. Her critical care follow-up had to be done at her house because she could not bear to be anywhere near the critical care unit. It was not just her life that she modified, she tried to get people around her to stay away from the things that triggered off unpleasant feelings in her. As already stated, she wanted her daughter to change out of the green top. She also insisted that the critical care follow-up nurse (whom she was very close to) walked to her home to conduct her follow-up rather than driving her car.

For a subset of study participants, there was also the situation where a previously innocuous element in life served as a trigger of their memories and/or experiences of their critical illness. These memories and experiences, being unpleasant, generally invoked feelings of depression (or as participant 12 put it “a black cloud”), anxiety and fear. As a result, aspects of life that survivors were fairly neutral to before their illness could be sources of emotional/psychological distress for them now.

For instance, the television was a trigger for participants 11, 13 and 19. Participant 13 put it this way, “...something like Holby City (a medical drama) on the television, I can’t even look at it, you know...H***** [his wife] was watching the other evening, she was watching something and, oh, that was it, it was Emmerdale...this girl’s meant to be in ICU and there’s one bed...I was in the kitchen and I could hear her. And I came in and it was just like the bed and all the machinery, and I just went, “Can you just turn that over?” I just didn’t even want to look at it, you know, and anything like hospital-related programmes, forget it, I don’t want to know, I just don’t want to know.”. Although it was easy to see why certain programmes on television, like the one just described, would act as triggers, sometimes even something that seemed unrelated could do the same, as seen in participant 11’s case. She associated an advert that featured fish and poverty with the nightmares she had had while

critically ill. This was because she had dreamt of a swamp and she linked the water in this advert to the swamp in the dream.

Television programmes were not the only triggers. Participant 11 also talked about how stress of any kind triggered off the nightmares she had had when critically ill, while the smell of disinfectant made participant 13 think of the critical care unit. As for participant 12, the trigger was another admission to the same ward she had been on following her discharge from the critical care unit.

As well as these more intense emotional/psychological responses, the opposite could occur in survivors where they experienced moderated and/or diminished emotions compared to previously. Participant 25 highlighted this particularly prominently. She said, "Emotions are completely dampened down. And I used to be quite a kind of up-down person, used to be bubbly and outward going and really have a laugh at work and get pleasure from things, but on the other hand, be quite moved by things. And now I feel quite whatever, kind of, you know...Feel quite numbed by the whole thing...I feel somebody's diluted everything apart from feeling anxious and upset, like somebody's died...I do feel like all my emotions have been diluted...I didn't ever want to be a straight line; I was always quite up and down...I had amazing highs and quite bad lows, not in a bipolar sense, but you know, on that spectrum and I did used to get over-excited and silly about things and I did get upset and I did get hurt...but that doesn't seem to happen any more.". Consequently, she appeared unruffled by what would have bothered her prior to her critical illness. She gave numerous examples reflecting this, from news about benefit cheats, to her landlord not fixing her toilet promptly, to her relationship with her partner not working out.

5.3.2. Personality

A few study participants spoke about how their emotional/psychological status had resulted in what they perceived to be a change in personality. Such participants included participants 11, 13, 24 and 25. Participants 11 and 24 said that they had been very outgoing beforehand, but since their critical illness, they had both become withdrawn and reclusive. Participant 11 said this about herself, "I was really outgoing; had a very dry sense of humour; got on with everyone. And now I won't make an effort to see the people that I used to see, or friends. I won't have friends; I won't make friends with anyone.". Participant 24 said, "I was so bubbly, I was so just-- loud. That's how I'd put it, bubbly and loud. That's me. That's what I'd have put me down to 18 months ago. And now I'd just put me down to just being lost and in a shell...it's not just me thinking it. People tell me, "You're just not V**** [participant herself],

where's V**** [again, participant herself] gone?"".

Participant 13 had been a very placid person before his illness. However, after his critical illness, he experienced big bursts of anger. He described the following during his interview, "At times when there's been blokes in front of me, I've actually said, you know, "Do you mind? I've come here to do my shopping, you know, not to hear your life story". And it has been that situation where I've thought, 'If he says one right word back to me, I'm going to punch his lights out', and, and that's how irritated I can get, and angry I can get. And, thank goodness, I've never, I haven't done it, you know, it's not in my nature to be like that at all, you know."

Like all the other survivors already mentioned, participant 25 also underwent a personality change. She went from someone who was "quite up and down" to a person who was "a straight line" (see earlier quote for more details).

5.3.3. Physical appearance

For some survivors, their emotional/psychological status affected their appearance. Certain survivors, like participants 11 and 25, lost interest in their appearance. Participant 11 talked about not bothering with makeup while participant 25 asserted that she was unconcerned when she had to leave the house looking "a state" even though it would have upset her before her critical illness. She also said that she would not mind attending a wedding with "half a head one colour and half a head with grey sticking out everywhere" and looking like "a back end of a bus". Besides a lack of interest on her part, participant 25 also had a morbid fear of the hairdresser's, which meant that her appearance was even more neglected from the point of view of her hair. From their descriptions, their appearances deteriorated after critical illness.

However, given the nature of their emotional/psychological status, none of the survivors so affected in the study appeared distressed by this change. Therefore, the impact of such a change on survivors' QoL is questionable.

On the other hand, there is still an argument for the inclusion of this effect when thinking about survivors' HRQoL, namely, there remains the theoretical possibility that a deterioration in appearance caused by emotional/psychological changes could result in subsequent further upset for the survivor concerned. For example, if a survivor was affected by the same fear as participant 25 but was interested in her appearance, he/she could be perturbed by the change in appearance. Although this was not seen in the survivors of this study, one should still be mindful of the possibility; just because a deterioration in appearance had been caused by emotional/psychological factors, one should not necessarily assume that there would

be no ensuing impact on survivors' sense of well being and their QoL.

5.3.4. Activities and behaviours

A. Types of activities and behaviours affected

According to study participants, their emotional/psychological status had a considerable influence on their activities and behaviours. Activities and behaviours that were affected can be classified into the following sub-areas⁴⁰:

- Posture and mobility.
 - Personal posture and mobility.
 - Using transportation.
 - Driving.
- Sleep/rest.
- Communication.
- Self-care activities.
- Activities associated with societal roles (such as domestic chores and activities, work and learning activities).
- Other activities.
 - Recreational and leisure activities.
 - Social activities.
 - Sexual activity.

The broad definitions⁴¹ for these sub-areas have already been highlighted in Chapter 4, Section 4.3.2, and are not repeated here.

In most cases, the emotional/psychological status of study participants was such that their activities and behaviours were restricted. Participants described three general scenarios in terms of restrictions:

- They felt uneasy doing something, although they continued doing it in much the same way. For example, participant 03 felt 'dubious about climbing', especially when it came to the steps she was using to do her domestic chores, but she persisted.
- They felt uncomfortable emotionally/psychologically doing a certain activity, and modified the way they performed the activity. Although the activity was carried out, participants remained conscious that they were unable to do it in the same way as they had done it before. Participant 25 gave a good

⁴⁰ For an explanation of why recreational and leisure activities and social activities have been left as two separate sub-areas despite their considerable overlap, please refer to Chapter 4, Section 4.3.2.

⁴¹ As in the kind of activities these sub-areas refer to.

illustration of this, "Like in the car, when we're all in together sometimes in the mornings, I can't stand it, so I have to, "Get the windows down kids." And I have pulled over a couple of times and just pretended I wanted something out of the boot, just to get out of the car. I'm okay if there's not somebody next to me in the front-they're just all in the back; but if somebody's there and somebody's there and somebody's there, they're all getting too big for this car, I need a bigger car, so I keep saying, "We need a bigger car."".

- They stopped performing the activity concerned or at least stopped doing it quite as much. For example, participant 11, due to many of her fears, would try as far as possible to avoid leaving her home or use any form of transport. Participants 23 and 24 shared participant's 11 reluctance to venture out of their homes; participant 23 due to incontinence and embarrassment from that, and participant 24 because of anxiety and fear.

Such limitations could sometimes be alleviated by contextual factors such as support from others. For instance, although participant 11 tended not to go shopping if she could help it, she would sometimes go if she were accompanied. Where contextual factors made some difference, this is highlighted accordingly.

Besides a limiting effect on survivors' activities and behaviours, survivors' emotional/psychological status could also result in them increasing the range and/or frequency of their activities and behaviours, although this situation was less common. For instance, participant 03 styled her hair more often than she used to because she had some hair loss and loss of her usual curls, and she was upset that her hair did not look like the way it had done before her illness. Whenever the sub-area had such increases in activities and behaviours, whether in frequency or in range, it is specified.

1. Posture and mobility

Personal posture and mobility, using transport and driving could all be restricted by survivors' emotional/psychological status. Where personal posture and mobility was concerned, it seemed that certain aspects were particularly prone to being affected by survivors' emotional/psychological status, namely, hand grip, bending/stooping, transfer activities and postural changes and getting up and down stairs.

The restrictions imposed by survivors' emotional/psychological status on this sub-area could sometimes be lessened by contextual factors in some survivors. For instance, participants 07 and 10 were unconfident about going up and down stairs, but they would do so when someone was with them. In addition, participant 07 also

laid a towel for grip at the bottom of her bath until she was confident that she would not fall when getting in and out of the bath. Another good example of contextual factors reducing limitations in this sub-area was in participant 13's case. In his words, "I don't like travelling on buses; there's so many toe-rags on buses nowadays. You get on and they're all sat there with the phones and MP3s blasting out, gangster crap as I call it, gangster rap. All the little chavs, I can't be doing with it. No, I can't be doing with it at all.". Much of his discomfort around the people whom he perceived as "toe-rags" and "chavs" stemmed from the fact that physically, he was not as fit as before, and he was anxious about not being able to defend himself. His reluctance to take buses was greatly reduced when he had someone with him, when he seemed far more at ease.

While there were quite a few examples of contextual factors helping survivors with personal posture and mobility as well as using transport, these factors appeared to play a lesser role when it came to driving; there were no clear instances in which contextual factors helped survivors who had stopped driving because of their emotional/psychological status, go back to driving.

II. Sleep/rest

The emotional/psychological status of many survivors was such that it generally caused their sleep to be disturbed. Anxiety, nightmares and dreams, racing thoughts, and intrusive memories and flashbacks were all cited by study participants as reasons why they were unable to sleep the way they used to before their illness. Participant 13, a good example of a survivor who struggled with sleeping after his illness, said the following, "My sleep pattern, that's one of the main after effects of my stay in critical care, is my sleep pattern being dramatically affected. I'll only sleep for about an hour, maybe two hours and then I wake up. And a lot of the time I wake up because I'm having nightmares. My sleep pattern's just all over the place. And it has been, on a daily basis really since I actually came out of hospital and came home. Probably only sleep really for about six hours once every fortnight where I'll have like six hours continuous sleep and then it's really like a short course in death where I'm totally zonked and then I wake up feeling really groggy and headachy. That's definitely changed, is my sleep pattern.".

A number of survivors who struggled with sleep were on sleeping tablets. They appeared to help in some survivors, like participant 19. However, for other survivors like participant 24, the benefits were less clear-cut. As participant 24 said, "I don't want to go to sleep 'cos I don't want to have that dream. I don't want to keep

dreaming the same things 'cos the next morning you get up and 'cos you've dreamt them things, you're so depressed, then the day's just ruined then...they've put me on sleeping tablets and everything but I find they sometimes make me feel worse, because I can't wake up as properly, and as awake as I like to, and then it means me having to go back to sleep and sometimes I don't want to go back to sleep because I don't want to think that I'll revisit that dream that I've just come out of."

III. Communication

For some study participants, their emotional/psychological status interfered with their communication with others. Due to various problems after their illness, survivors such as participant 13 and 23 would get very self-conscious and uneasy when they had to communicate with others. This would be worse when they were communicating with people they were not familiar and/or comfortable with. Participant 13 put it in this way, "I get very self-conscious and my stammer comes on more when I'm with other people who I'm not that familiar with, and I was never like that...when I'm speaking to people, I start stammering and it gets worse and then I get very self-conscious of it. And that makes it worse and then, I'm having to think. I never used to have to think about what I was going to say, you know, a conversation was just I open my mouth and it'd just all fall out, you know...Now I think about what I'm going to say, and I find that really frustrating that I have to consciously think about what I'm going to say to certain people, you know. Yeah, that's a bit of an issue really...if I meet somebody for the first time I've got to kind of rehearse in my head what I'm going to say because if I don't, I know that I'm going to get flustered and then when I get flustered, I stammer and then I don't know what to say...". Participant 23 was similar; she was better with her communication when she was talking to someone she was comfortable with, like her long-term partner.

IV. Self-care activities

For some survivors, their self-care activities were restricted by their emotional/psychological status. The types of self-care activities affected included:

- Washing oneself (bathing, showering, drying, etc). For example, both participant 10 and 23 wanted someone in the house with them before they would take a shower/bath.
- Caring for body parts (brushing teeth, shaving, grooming etc). It has already been described earlier how participant 11 and 25 stopped some of their grooming habits like applying makeup because they had lost interest in their appearance (Section 5.3.3 has further details). In addition, participant 25, due

to a deep phobia of the hairdresser's, stopped going to get her hair done (again, details in Section 5.3.3).

- Feeding oneself, eating and drinking. Participant 11 and 13 both spoke about not eating, participant 11 because of high levels of anxiety and participant 13 due to his depression over his limitations.
- Looking after one's health (taking medication, going for medical appointments, engaging in physical exercise and sports⁴², not indulging in health risking behaviour such as smoking and drinking excessive alcohol, etc). Participants spoke about finding it difficult to seek medical help as well as indulging in unhealthy habits. A good example of a survivor struggling with the former was participant 11. Due to anxiety and fear, she would not go to hospital to seek medical help when she required it or even for her follow-up appointments; her critical care follow-up was done in her own home. Her words about this were, "So what I tend to do now is, because I'm so scared of going into hospital, I leave it till the last minute and then it's always ITU or always HDU, and that is taken out of my control, then because, as I usually lose consciousness and somebody phones an ambulance and I have no control over that. But, if I had, I'd never go; I'd never go into hospital, never, not after what happened.". As for the latter, participant 13 was the prime example. His critical illness was due to him drinking excessive alcohol, so it was not a new problem for him. However, after his illness, he became very depressed over his multiple health problems, and subsequently, that led to some episodes of binge drinking. One such episode resulted in him being re-admitted into the critical care unit for observation.

Other than limiting their self-care activities, survivors' emotional/psychological status could also result in an increase in self-care activities. Participant 08 and 24 both described such an increase. Participant 08, due to her anxiety about having another hypoglycaemic attack and a recurrence of her critical illness, checked her blood sugars so much initially that she said this of her fingers, "My fingers were an absolutely mess...they were just covered in scabs. It was like where shall I prick this time? You know, where's a gap?". As for participant 24, she was obsessed about keeping her hands clean and her surroundings clean ever since her critical illness

⁴² As already mentioned, engaging in physical exercise and sports does not just fall under the realm of self-care. For some survivors, it was something they really enjoy doing, and therefore, it can be classified under recreational and leisure activities too.

because she was worried that she would get ill again otherwise.

Whether self-care activities were restricted or increased, contextual factors could make a difference. For instance, participant 12 had some anxieties about being back in hospital again for further medical treatment. After talking it through with the critical care follow-up nurse who helped address these anxieties by suggesting feasible solutions, she no longer dreaded her upcoming admission into hospital. However, the impact exerted by contextual factors could vary. Some participants such as participant 11 had very deep-seated fears. Therefore, although she had had a lot of help from the same critical care follow-up nurse (she was seeing the critical care follow-up nurse twice a week at the time of her interview, with telephone contact available to her 24 hours a day), she was still unable to return to the hospital. As already stated, all her follow-up was being done in her home.

With regard to helping with the increase in self-care activities, participant 08's worries about recurrent hypoglycaemia and her subsequent obsessive checking of blood sugars were alleviated by the input of a diabetic nurse. This nurse gave her strategies that would reduce the chances of her hypoglycaemia being undetected and/or unmanageable. This gave her the reassurance she needed which, in turn, helped with her tendency to keep checking her blood sugars.

V. Activities associated with societal roles

In the study sample, survivors' emotional/psychological status influenced the following activities associated with societal roles:

- Domestic chores and activities.
- Learning activities.
- Work.

As previously mentioned, the type of activities applicable to a given survivor differed, depending on their characteristics and circumstances.

Again, as in the case with self-care activities, the emotional/psychological status of survivors could result in both a restriction and an increase in this sub-area of activities, depending on the precise emotional/psychological change.

In terms of experiencing restrictions in these activities, participants 11, 13 and 24 were all good examples of survivors who limited their activities associated with societal roles after their illness. Participant 11 had become a virtual recluse in her own home, and would try as far as possible to avoid going out, even to do crucial chores like shopping. In her words, "Wouldn't go anywhere shopping or anything like that with her [critical care follow-up nurse]. No, no, no...I like to go with two people. One

that knows how to deal with epilepsy. And one that would know how to deal with me if I actually became quite emotional, which I do, 'cos I don't like people being next to me or touching me or anything like that...I don't like going out. In fact, if it was my choice, I wouldn't go out at all. But, obviously, at some point, I do have to go out, but the majority of the times, I stay here, and make them come to me.". Participant 24 was similar; at the time of her interview, her young daughter (15 years old) was doing the shopping, with her only going to the shops when she absolutely had to. In addition, her heightened anxiety was also making it impossible for her to even contemplate going back to work (she was managing a pub before her illness).

As for participant 13, he also found it very difficult to do certain chores like shopping, especially if he had to go alone. In his words, "I can get very, very anxious, especially in queues, my tolerance seems to have just gone right down and I just get very self-conscious like people are looking at me. And then it's racing round in my head, you know, why is it that when a woman goes to the till she never has the money ready, it's like, got to root through her handbag to find her purse, and then she's got to root through and putting all these coins out, and I'm just thinking, 'For God's sake, woman, get organised', you know, and it builds, and it builds, and then the sweat starts pouring out of me...it gets me at times, when I do get anxious and either get palpitations and racing head, racing heart, start really sweating profusely and then everybody's looking at me in my mind, everyone, and I just want to run, hide under a stone or just escape the situation and more often than not, I'll come back here and I'll be like, "Phew, that was horrendous", and sit down and calm down a bit...never used to be like that before really, not at all.". At the time of his interview, he had organized his life such that someone would go shopping with him, and help him queue and pay.

In addition, he had to stop his course in counselling (learning activities) because his cognitive problems were preventing him from engaging in his classes effectively, which was, in turn, inducing anxiety and panic in him. As he said, "I actually signed up to do a college course. I was going to do an introductory to counselling. Just to do something on a Saturday afternoon. And I went for three of the lectures and it screwed me up. Because what the lecturer was saying and what we were reading, two minutes after I had completely forgotten. And I'd have a question on that and I couldn't remember what the answer was. And then I'd go back and I couldn't remember what the question was. And I was just going round in a circle. And within three weeks I was three weeks' behind in the work. And I thought "This is ludicrous". Because I was coming home worrying about that. Panic attacks. Anxiety

attacks. "Oh, shit, I've got to have this done and I've got to have done and I've got this assignment to do". And I could not...and I just thought, "Woa, woa, woa, just hang on a minute. This ain't conducive to your well-being. You know, you've got to just knock it on the head and take stock". So I deferred it until next year."

When it came to increasing this sub-area of activities, this was most obviously seen in participants 10, 17 and 24. Participant 10 had started taking swimming lessons and was starting to make plans about learning how to drive as well as ski (learning activities). This was due to the fact that she felt that she had been given a second chance in life and that she should make full use of it.

Participant 17 became much more aware of her mortality after her illness and started putting some of her affairs into order. As she said, "It's made me realise that we can all go just like that, you know, and that I could have died then, yes, so easily, that would have changed everybody's lives. And I think of things like the state of this house and all the...I call it junk, but all the stuff I'd have to get rid of because I definitely don't want to saddle any of the children with having to clear this house...as I say, I want to make sure everything is in order, that they don't have any extra difficulties, legal difficulties or a lot of work to do, and I've done a will. I've made my wishes known. They know where to find any documents...yes, it's woken me up to the fact that I have to consider how they will manage and so I want to make it easier for all of them if I can."

As for participant 24, she was worried about becoming ill again and therefore was doing a lot of cleaning (domestic chores and activities).

There were no clear examples of survivors increasing their work activities because of their emotional/psychological status.

It should be noted that survivors' emotional/psychological status could have differing effects on different activities in this sub-area. Participant 24 was a good illustration of this. Due to her aversion towards being around other people, she would not go out to shop or pick up her daughters from school as far as she could help it (limitation in domestic chores and activities). However, she had a deep fear of being critically ill again, and consequently, was obsessive about cleaning her home (increase in domestic chores and activities).

In terms of the role of contextual factors in this sub-area, it has already been briefly touched on above. The restrictions in this sub-area of activities may be reduced in some survivors when certain contextual factors are in place. For instance, participant 11 and 13 would go shopping and/or find it easier to do so when someone

went with them.

VI. Other activities

a. Recreational and leisure activities

In some survivors, their emotional/psychological status resulted in them not carrying out the recreational and leisure activities they had been engaged in before their critical illness. For example, participant 09 stopped reading as much as he used to. This was what he said during the interview, "...I don't have much interest in reading at the moment. I couldn't, it just doesn't appeal to me. Even the newspaper, I can just open it up, glance through it and put it down again and that's it. I don't feel like reading a lot, no...I just lose interest after I've start--, read a couple of pages or something like that. I just lose interest in it. Why or not, I don't know. I used to like reading books and everything at one time. At one time I used to read the newspaper from back to front but I just glance through it now. I'm still not back to normal with my reading.". Participant 20 was similar, but in his case, it was exercising; he stopped exercising because he lost the motivation to do so.

In contrast, in other survivors, their emotional/psychological status actually increased their recreational and leisure activities. Participant 10 spoke about taking up swimming. As she said, "...something I've always wanted to do was learn to swim. So when I managed to get out on my own, without my shadow, I went to The Forum and I booked myself on a course of swimming lessons, of which I've had three so far...I look at it from the point of view I've been given a second chance. People worked hard to give me that second chance. I haven't the right to sit around and do nothing.". Her outlook of being given a second chance was the motivational force behind her taking up more activities that she would enjoy, which included swimming. In addition, as mentioned earlier, she also planned to take up driving and ski-ing because she felt that she would enjoy doing these activities.

b. Social activities

Depending on the particular emotional/psychological change that had occurred, survivors could end up restricting their social activities or increasing them.

Good examples of survivors who experienced a restriction in their social activities included participants 24 and 25. Ever since her critical illness, participant 24 had developed claustrophobia and she found interacting with people difficult. As she said, "I don't like socialising, I feel claustrophobic. I don't like being out...it's this feeling of getting close to people all the time. I don't want to get close to people, so if I go out, it's personal closeness and emotional closeness that I'm interacting with all the

time because you're speaking to people and you're stood next to people when you're out, and it's them barriers you've got-- I keep them round me and I can't seem to let them-- I don't want to let them down.". Consequently, she had stopped engaging in social activities compared with before her illness.

As for participant 25, she stopped seeing most of her friends because she "can't be bothered with anything". In her words, "I don't see my friends any more, don't bother with them. Don't bother with anything now...I see one friend-- it's a fib actually, I do bother with one person. I see my sister and I see one friend-every holidays, I see her, every seven weeks, 'cause she's a psychiatric nurse who has had another baby and has got severe post-natal depression, so she's quite therapeutic. Not that we ever say anything; it's the company's therapeutic, so I see her for a couple of hours and then we'll go off on our merry ways. But I can't be bothered with anything.".

In contrast, there were also survivors who increased what they did with others. Participant 07 and 10 were both such survivors. Participant 07, after her illness, tended to spend more time with her family than she had done previously. As well as being more aware of her own mortality, and the mortality of those around her, she also had a change in outlook where she placed higher importance on spending time with people compared to say, doing domestic chores and activities. Participant 10 had also undergone a similar change. As she said, "...there's about four or five of us now as a family, little family group, and we try and go out for a meal once a fortnight which didn't happen before I was ill at all, and that's my sister, my sister-in-law, my daughter, my daughter-in-law and myself.". As evident from the extract, she was engaging in social activities that she had not done before her illness⁴³.

Contextual factors had a small role to play in this sub-area of activities. As activities in this sub-area were done with others, what other people did (or did not do) could help determine whether survivors were able to engage in these activities. For instance, participant 10 had been able to get together with her daughter only because her illness had resulted in ending the longstanding estrangement between them.

⁴³ Paradoxically, however, this did not mean that there was an overall increase in her social activities. This was because her physical status was such that she was not attending all the social activities she used to before her illness. Therefore, while she might be attending new social activities, she was also omitting some of her previous social activities, which meant that on balance, there might not be a clear increase in what she was doing on a social level.

c. Sexual activity

Survivors' emotional/psychological status also affected survivors' engagement in sexual activity, particularly in the case of female survivors. In contrast to the situation with male survivors, where physical factors seemed to have a strong(er) role⁴⁴, the female survivors who spoke about a decrease in sexual activity tended to attribute it to their emotional/psychological status. Participants 24 and 25 could not bear close physical contact; participant 24 said it made her "cringe" while participant 25 commented at least a couple of times through her interview that it "made her stomach turn" and "her skin crawl". As for participants 12 and 23, they had marked body image issues, which meant that they were averse to being seen naked. In fact, participant 23 described an incident where she had got into a bath that was too hot, and how she did not call for her partner to help because she did not want him to see her without her clothes on.

That is not to say that only the sexual activity of female survivors was affected by emotional/psychological changes. Participant 13 not only had problems with impotence, but also admitted that he had had a very low sex drive since his illness (in strong contrast to what he had been like before his illness). Therefore, him not engaging in sexual activity was at least in part due to his emotional/psychological status.

B. Balance of activities and behaviours

Before concluding this section on 'activities and behaviours', it is worthwhile highlighting that with the changes that have already been discussed, it is almost inevitable that there was some change in the balance of activities and behaviours survivors engaged in. This shift could be *imposed* on survivors by their emotional/psychological status, or it could occur because survivors had *chosen* to shift this balance consequent to their emotional/psychological status.

An example of the former situation is seen in the data provided by participant 11. Before her multiple critical care admissions, she was an outgoing person who enjoyed socialising with friends and ran her household independently. After her critical care admissions, she spent long periods of time thinking about her dreams and nightmares; "My life now--, it's really difficult; you have your good and your bad days. I constantly think about it. Don't think about anything else. Constantly sit and think about it. I'll sit here dead quiet, just doing nothing, waiting for my little girl to come

⁴⁴ Both the men who spoke about having poor sexual activity had cited impotence as (one of) the reason(s) for this issue.

home, and I will constantly think about the dreams, especially the one with C*****.". She tried not to leave her home without two people with her and did not see her friends. In her words, "I've had three admissions to intensive care...the first one, I was 26...and that completely changed, ruined my life, absolutely ruined my life."

In contrast, in the latter case, the change in balance of activities was not so much inflicted as a choice. This was pertinent to survivors such as participants 07 and 10. After their critical illness, they both had a change in outlook in that they placed higher importance on spending more time with people compared to doing their household chores. As participant 10 put it, "I went through a period, I think, where I thought to myself, "Well, people are more important than doing household chores," if you get what I mean. I was quite content if I saw people or, people became very important to me, whereas I thought, "Well, yeah, okay, the ironing wants doing, our J*** wants to come, I can do the ironing tomorrow. J*** came to see me in the hospital. She's more important than me ironing,"...It was sort of that philosophy.". Participant 07 expressed similar sentiments. They both chose to do more activities with others as compared to the time before their critical illness.

Appreciating the reasons why shifts of the balance of activities have occurred is important, because they have different implications for survivors' QoL. A shift in the balance of activities affected survivors' QoL negatively when it was imposed on them whereas a shift by choice either increased or had a neutral effect on their sense of well being.

5.3.5. Physical zone of comfort and/or activity

Many study participants commented on how their emotional/psychological status after critical illness had affected the physical zone they felt comfortable in, and consequently, in certain cases, their zone of activity. Survivors who made such references talked about how they were less at ease in many places and therefore, for some of them, they were more confined to certain areas (the area survivors were comfortable in did not automatically equate to their area of activity, as some survivors still chose to move around in certain locations despite their distress).

The extent of restrictions varied tremendously among survivors. On the one

hand, some survivors were only mildly restricted⁴⁵. An example of such a survivor was participant 07. She had some anxiety about her critical illness recurring, especially given that no cause had been found for it and she felt that there was nothing she could do to prevent it. As a result, she had reservations about going abroad. As she said, "What if they don't find a cause, what do I do then? You're living on a knife edge. You think, well, it could happen again. So you're kind of, well, as I said to you before, insurance problems for going abroad on holiday, would I want to be abroad when it happened...So you think, "do I book a holiday to go away?" I mean I know you can't do it for 12 months because no insurance company will insure you for 12 months, but you think, if I can... if it's not too expensive to insure myself to go away, do I want to go away abroad?". Other than going overseas, her interview data indicated that her anxiety about it happening again did not stop her going anywhere or make her uneasy about being in any place. She appeared to be quite comfortable wherever she was, as long as she was within her own country.

On the other hand, a number of survivors found that they were incredibly restricted in the places they were comfortable with, with some survivors virtually confined to their homes. Participants 11 and 24 were prime examples of such survivors. Both of them had a deep sense of claustrophobia around people (excerpts demonstrating this have already been presented earlier), which meant that they tried to spend as much of their time at home as possible.

Others such as participants 13 and 25, despite feeling relatively comfortable in their own homes compared to being out and about⁴⁶, did get out of their homes. However, these survivors found that they could get fairly distressed in several other places, particularly locations that tended to be crowded and/or gave them less personal space. The following were excerpts from their interviews, which demonstrated this well.

Participant 13:

"Most of the time I won't go out of the house by myself because I get a lot of anxiety,

⁴⁵ There were survivors who appeared to be comfortable in the same area of activity as they had been before, i.e. they were unrestricted. For example, participants 15 and 16 spoke about travelling overseas for holidays. However, given that this section is about restrictions, the two extremes were taken as mildly affected to severely affected.

⁴⁶ They both still raised examples of getting distressed at home. Participant 13, due to his lack of sleep, very often experienced hallucinations and consequently some paranoia while at home. Participant 25 suffered from feelings of anxiety and panic when her children were physically too close to her at home. However, they both seemed to be more at ease in their own home than out and about.

can't walk as fast as I used to do, very aware of people bumping into me, and I have had it where people just barge into me and 'cause my left leg's a lot weaker, you know, quite often I've been like, you know, knocked over kind of thing, but I can get very, very anxious..." and then later in the interview, he also said, "I have to be very, very conscious of it and not go into situations that I know are going to create anxiety, not going in shopping centres, he [meaning his son] hates shopping centres, hates the hustle and bustle of people and I'm the same, now, really, I don't like to go in shopping malls or anything like that."

Participant 25:

"...it never used to bother me, kind of tactile people, but now I just have got a bigger personal space bubble. But as far as partner's concerned, I couldn't stand being touched or hugged and having to have avoidance strategies...it makes my stomach turn and my skin crawl and I just wanna scream...when the girls keep holding on, then it's a slight panic of kind of a-- if you analyse it's kind of like a fight or flight kind of thing" and she also went on to say, "I don't go to crowded places, no, any more. But I used to go to the Trafford Centre shopping...I don't go clothes shopping, don't go into town...I don't like it, so I don't--. Once I went shopping and for some reason the time I normally go it was really busy and I ended up leaving my trolley with food in 'cause I just couldn't stand it...it's normally quiet at that time. It was heaving and I left my trolley. I've done it twice actually, I've done that in A*** once, I left. I actually got to the checkout that time and I put it on the thing and everybody was like-- I just said, "I'm really sorry, I've changed my mind, I don't want it any more."...I was quite happy going out clubbing and pubbing and--, more than happy to-- no, it never bothered me. But then I don't think-- I just don't do it any more...Like in the car, when we're all in together sometimes in the mornings, I can't stand it...I keep saying, "We need a bigger car.""

For some of the survivors whose physical zone of comfort and/or activity had been restricted, this restriction could be reduced if they were with someone they trusted. For instance, both participant 11 and 13 spoke about being more comfortable about leaving their home when accompanied by others.

There were two points of note regarding the impact of emotional/psychological status on this area. First, it may be tempting to use a person's place of residence as the starting point, and move outward when thinking about the

impact of emotional/psychological status (much like the impact of physical status on physical zone of activity in which many measures of physical status and functioning have a degree of reference to a person's home⁴⁷). However, when it comes to the impact of survivors' emotional/psychological status, the situation is not quite so straightforward. The data clearly indicate that being distressed inside one's home (and/or being unhappy to move around freely within one's home) did not automatically equate to being uncomfortable outside one's home (and/or being unhappy to be outside)⁴⁸. In other words, it could not be assumed that someone distressed in their own home would definitely have a smaller area of comfort and activity than someone who was comfortable in their own home (compare this to the situation with physical status where if a person was confined to bed and could not move freely at home, they would definitely have a smaller area of activity than someone who could move around freely in their home).

Participant 05's and 11's cases were concrete examples that demonstrated this well. Participant 05 had claustrophobia after his critical illness and suffered from feelings of panic at home and outside his home in crowded places. However, other than his avoidance of swimming baths which stemmed from his anxiety of contracting Legionella and becoming critically ill again, he appeared to be happy to move around a wide physical area fairly freely; he did not give any indication during his interview that he avoided crowded places or tried to stay outside his home. In fact, from what he said, he seemed to spend a lot of time in his home despite getting feelings of anxiety there.

In contrast, participant 11 was fairly comfortable being in her own home. As it happened, it was clear from her interview that her home was the only place where she was comfortable. Accordingly, her area of activity tended to be mostly within the confines of her own home. Therefore, she had a smaller area of activity compared to participant 05 despite her ease in her own home and his discomfort within his.

Second, when talking about the impact of emotional/psychological status on this area, survivors merely spoke about restrictions. None of the survivors talked about an increase in their physical zone of comfort and/or activity although one survivor in particular, participant 10, did mention trying new activities like swimming due to her

⁴⁷ Whether one is confined to one's own residence is indeed a good approximation of how much distance/area one could cover where physical function is concerned. Moreover, distance/area measured in such a way is very relevant for most people.

⁴⁸ Compare this with the case of physical function where being unable to move around freely in one's own home means that one is also unable to move around outside.

outlook of being given a second chance. Therefore, it would appear that she was at least making trips to the swimming baths (a new place), which she had not visited before her critical illness. However, she did not flag this up as an expansion of her physical zone of comfort and activity (she did speak about trying swimming as a new activity). It might be that trying new activities was more important to her than visiting new places.

On the other hand, she also mentioned that she was not comfortable travelling overseas when she had been before her illness. In fact she had been preparing for a trip overseas when taken ill. Therefore, she technically did not have an increase in her physical zone of comfort and/or activity, but suffered a decrease. This might also be why she did not raise this as a change after critical illness. Therefore, before concluding that an increase in a person's physical zone of comfort and activity was truly not important to survivors, it would be worthwhile looking at this in more detail. Given that participant 10 was the only person in the sample who provided any insight into this aspect, it would be remiss to form any definitive conclusions from this person alone.

5.3.6. Interactions and relationships with others

It was clear that for several study participants, their emotional/psychological status after critical illness had significantly modified their interpersonal interactions and relationships. In this subsection, these patterns of change are explored.

A. Changes in number/frequency of interactions and relationships

The interview data indicate that there were changes in the numbers/frequency of survivors' interactions and relationships consequent to their emotional/psychological status. In some relationships, interactions decreased, sometimes to the extent that contact completely ceased. Participants 11 and 25 were examples of survivors in whom some relationships were thus affected. Participant 11 said, "...now I won't make an effort to see the people that I used to see, or friends. I won't have friends; I won't make friends with anyone. And I'm quite isolated and, at the moment, that's the way I want to be.". Saying that, she had kept some of her relationships going; in fact, there was a group of people very integrated into her life. It was just that from the above excerpt, it looked like she had not maintained all her previous relationships to the same extent.

Participant 25 was similarly affected; she was only regularly seeing one friend (see earlier extract on this). She also mentioned, during her interview, another friend whom she had spoken to every week before her illness. After being ill, this had

dwindled to once a month in the last six months, partially because of a loss of desire to connect with this friend.

In contrast, interactions within some existing relationships could also increase. Participant 07's interview revealed such an example when she commented, "I used to get uptight about things... I mean I always did spend a lot of time with my grandchildren, but if, say, V****[participant's daughter]'ll say, "Do you fancy going somewhere to...?" If I've got a mound of washing waiting to be ironed up to the ceiling, I'll say, "Yeah, okay." Whereas before I'd say, "Oh, no, I've got all these jobs to do." The house'll be here when I'm not, the jobs'll be here when I'm not."" She appeared to be spending more time with her family after critical illness.

Besides intensifying interactions within relationships already present in their lives, some survivors also commenced and built new relationships. Many of these relationships were with the clinical staff who had been looking after them. For instance, participants 11 and 23, because of their need for emotional/psychological support, had formed new, fairly close relationships with the critical care follow-up nurse after their critical illness. Scattered through their interviews were frequent references to this particular nurse, indicating her importance in their lives. In fact, participant 11 spoke about how her last admission into critical care was particularly difficult because one of her nightmares in that admission involved this nurse dying. This demonstrated the crucial part this nurse played in her life. The relationship was obviously a new relationship that would not have been built up if the emotional/psychological status of these survivors had not driven it.

Before moving on from this discussion on the amount of interaction within relationships, two important points should be highlighted. First, not all the relationships within a survivor's life followed the same trend. Often, a survivor interacted more with some people while decreasing his/her dealings in his/her other relationships. For instance, participant 11 stopped seeing her friends but saw the nurse following her up as often as twice weekly.

Second, this variation in the amount of interaction could be fairly dynamic with survivors going from interacting more to interacting less in any given relationship. Participant 10's interview clearly demonstrated this. She talked about spending time with people in her life rather than doing her household chores as a result of her change in outlook. This gave the impression that she had increased how much she associated with her friends and family. However, she also spoke about having days that she could not be bothered with anyone. During those times, she would have been

dealing with the same people less than she would have done before her illness. It might well be that if she was asked this question directly, she could definitively say whether the amount she was interacting with others had changed and whether it had increased or decreased. However, the fact remained that there might be a temporal variation⁴⁹ with this.

B. Changes in nature of interactions and relationships

Besides changing in numbers/frequency, survivors' interactions and relationships also underwent a change in nature. One such change was the degree of closeness and attachment within survivors' relationships. Closeness could refer to physical closeness, emotional closeness or both. Emotional/psychological factors drew people together as well as alienated them. However, it must be said that there were not as many examples of people being brought closer by emotional/psychological factors as there were instances where people were being driven apart.

People being drawn together are looked at first. Participant 11 was an example of a survivor who became emotionally very close to someone in her life. Due to her many emotional/psychological problems, she required immense support and became extremely reliant on the critical care follow-up nurse providing that support. Consequently, that also led to a very strong attachment and a degree of closeness⁵⁰. Strictly speaking, her emotional/psychological status did not directly motivate her to open up and get closer to others, if anything, it prevented her from seeking help, "I actually thought I was losing my mind, and it was separate to what had happened in intensive care. So I kind of separated the both. I thought, "Right, well keep your mouth shut about that and just explain physically what's gone wrong"...I wasn't very forthcoming with the information because I thought they'd use that against me...I thought then that my experiences were not what other people had had in intensive care, so I just thought it was me. So I kept quiet.". However, her emotional/psychological status meant that she needed help and this placed her in a vulnerable position. It seemed almost inevitable that she would become very reliant on, and have a very close relationship with the person who could help her, which was what did end up happening.

With regard to survivors becoming more distant from people in their lives, a

⁴⁹ Temporal variation in the changes experienced by survivors is further highlighted and discussed in detail in Chapter 9.

⁵⁰ Many of the emotional/psychological problems required the survivors to trust and open up to people to a huge extent in order to be helped. This inevitably meant discussing very private matters, which in turn led to a sense of closeness in a lot of cases.

number of survivors highlighted this. The lack of closeness could be emotional, physical or both. The following extracts clearly demonstrated this.

Participant 12:

On physical closeness: "...the physical side of the marriage, 'cause there's been no physical side since this has happened but J*** [participant's husband] wanted to cuddle and I didn't, I kept pushing him away all the time...It's like when he wanted to cuddle me and I pushed him away and he just keeps saying to me all the time "You're still you. I'm just made up that you're here". He said, "I wouldn't have cared if you'd have came out of that operating room with no legs or anything, as long as you were still there". But I just kept thinking, "Ooh, how could he want to cuddle me with this?""

Participant 24:

On emotional and physical closeness: "I don't want to get close to people, so if I go out it's personal closeness and emotional closeness that I'm interacting with all the time because you're speaking to people and you're stood next to people when you're out...it's them barriers you've got-- I keep them round me and...I don't want to let them down." and "I don't let anyone in no more...And then 'cos of that I feel on my own a lot of the time. And I never had these feelings."

On physical closeness: "...people will say to me, "You have not had sex for nearly two years and you're telling me it doesn't bother you." And I'll go, "I didn't say it didn't bother me," but the thought of having anyone near me makes me cringe as well...I don't want to get close to anyone, but I miss the fact that no-one's there to give me a hug or kiss or snog, just generally...But the thought of having it makes me go, "Oh, oh," and cringe."

Participant 25

On emotional closeness: "I thought I would actually feel closer to them instead of more distant. Obviously, you don't let on 'cause that would be really hurtful-- 'cause they feel closer I think, whereas I don't, I feel more distant towards my family and friends. I just don't feel anything for anyone anymore."

On physical closeness: "It just makes my skin crawl. It does. Even with-- like I was saying, the girls, even my girls, they come—, it turns my stomach...it does make my skin crawl and makes me feel-- I just want to say, "Get off!" and just go away and on

there, it's just like, "Whoa," on the sofa together, it's like horrible, and almost to the point of having to get up in a panic and kind of mask it because I obviously don't want to upset them...and hugging them, they just want these hugs and it's like I do, but inside I'm like thinking, "Oh my God, how much longer can I stand of this?"...And you know when you pull away for the end of a hug and they keep hanging on and it just really irritates and frustrates me to the point of I want to shout, "Get off!" but obviously you don't. You go, "Oh darling, you know, come on, you've got to lie down now." Or sometimes when they shout for a last hug and I've been in once and I used to go in again and give them a last hug, sometimes I pretend I haven't heard...But on a personal relationship, you know, with your partner, I just don't even bother masking it...Well, I do, I suppose, yes, I do. But to a lesser extent."

As these extracts have demonstrated, survivors' emotional/psychological status could have devastating consequences for their closeness with others, even to the point where a mother could not bear to be near her own children.

The level of dependency and reliance on others also altered in many survivors. Many survivors were more dependent on others due to their emotional/psychological status. For instance, participants 07, 08, 10, 11, 12, 13, 22 and 23 were all survivors who, because of confidence and anxiety issues, needed certain people around a lot more than they had done before their illness. For some of them, even if other people were not physically there, just the thought that they were contactable (by phone, text, etc) provided enough reassurance for them to get on with life.

Examples from two of these survivors give some idea of survivors' reliance on others. When speaking to participant 08 on the topic of her anxiety about getting another hypoglycaemic attack, she said the following, "It's completely gone because I trust in that (techniques given to her to help her prevent her hypoglycaemic episodes from spiraling out of control) and I must admit the diabetic nurse that I know, that I used to go and see in clinic, she started coming to visit me weekly...and I knew she was always at the end – and she still is – always at the end of the phone. I've actually got her home number and her mobile number, if I actually need it.". Participant 11 was the same, as seen in this extract from her interview, "I have such a reliance on her [the critical care follow-up nurse] as well, which isn't a good thing either. But I have to have her near me, nearby. If ever I get into any bother or anything like that I just text her and she texts me back, or she'll get on the phone, or she'll come round. Even at weekends and her days off, she does that. She's there any time. She leaves her

mobile phone on 24 hours a day. And she went to *****, with her mobile phone, and she'd text me from ***** to make sure I was okay."

In contrast, there were also survivors who, due to emotional/psychological issues, became more independent of the people around them⁵¹. Participant 25, who was such a survivor, said this, "And it's bizarre because I used to need M*****'s dad, S*****, more than he needed me...And, you know, we had planned to move in together and I did feel things when he said things that were upsetting...and then I didn't-- to the point where I didn't actually make any effort at all...I'd have been devastated if we'd split up before this, not in terms of oh, I couldn't cope, because I've always done, the children-- always been fiercely independent with the girls and financially fiercely independent, but I would've been upset, but not any more...I feel like I should be sad but I'm not-- about a relationship...he used to say, "Did you miss me?" you know, if he hadn't been round a couple of-- "No.", just go, "No." And he's so hurt and I say "I'm sorry, I don't mean to hurt you." So he said, "So did you miss me?" And I just couldn't lie 'cause I'm useless at lying. I used to say, "Well, no, I didn't because I was busy," but it wasn't that.". She was clearly much less emotionally/psychologically dependent on her partner than she had been, possibly because she felt emotionally numb and distant from most of the important people in her life.

Another clear trend in the area of interactions and relationships was the increase in conflict between the survivors and others. This was seen in quite a number of survivors who participated in this study. For example, participants 07, 10, 12, and 19 were all angry at the way their families were treating them and this frustration led to clashes between them and their families. In participant 13's case, his anxiety would translate into irritability and that resulted in confrontations, as reported by him in the following extract: "...my anxiety levels if I'm not careful, can like just up, can flip, you know...but I am aware of it, I am aware of it and I do try and bring myself down and, avoid confrontation at all costs, I really do...It hasn't exploded into physical confrontation, but it's exploded into verbal confrontation when I've got angry.". Participant 17, due to her disbelief in her daughter's version of events relating to her illness⁵², had what she called a "head on conflict" with her daughter.

⁵¹ This happened less among the survivors who took part in this study than the scenario of survivors becoming more reliant, however, whether this was a true reflection of what was happening generally among all survivors would need further study.

⁵² She was unconscious for most of her illness and was totally unaware of what was happening. As a result, she did not believe that she had been so ill.

Survivors also changed with respect to how open they were with, and towards others. In general, survivors of critical illness, for various emotional/psychological reasons, became less upfront (in terms of their communication), less receptive (in terms of taking in information from others) and less trusting, especially when it came to issues related to their illness or any future management.

Participants 11 and 12 were both examples of such survivors. Participant 11 kept quiet about her emotional/psychological problems after critical illness not only because she thought that no one would have wanted to know, but also because she thought that she was going insane. She talked about having to “act differently”, “put a brave face on” and “show the world something differently to what you actually are”.

Participant 12 kept her worries about her future operation to herself because she wanted to protect her children. This is what she said during her interview, “I feel upset and, I feel angry that I think ‘Why should my sons have to be going through this?’ and I know they’re worried sick about the next operation I’ve got to have but, all they say is “No you’re be alright, you’ve been alright before”, but I know deep down that they’re worried sick, so is J*** [her husband], and I just think it’s not fair. Why should they have to be going through this? So I put a face on for them as well...I’ve told J***[her husband], but I would never dream of sitting down and saying to the boys ‘I’m really frightened about the next operation’ and everything because I wouldn’t want them to be worrying. I wouldn’t want to upset them...I keep a lot back because I try to protect them...”.

Participant 12 was not only less upfront about conveying information, she was also less open towards accepting information from others. For example, she was more skeptical about what she was being told by the surgeons as seen in what she said, “I can talk and say to them “No, you’re not touching me.” and everything. Whereas like last year, I wouldn’t have dreamt of questioning a surgeon. I honestly wouldn’t have dreamt of it. My oldest son was asking Mr ****[the surgeon] loads of questions, and I wouldn’t have dreamt of doing it and, and my son was writing his answers all down and Mr **** [the surgeon] was saying to him, joking, “Oh you’ll be after my job soon” and I think it’s a different generation because we’ve been brought up, you don’t question a doctor or you don’t question anyone like that. Whereas your generation, like my son, said, “No”, he said, “I want to know what’s happened to my mum.” and, and he didn’t think twice of asking these questions, whereas we didn’t and like everything he said we just said okay to...And it was only after he’d [another surgeon, different from the surgeon already mentioned] explained it to us and everything that I

thought it's not us in the wrong...that's when we started asking the questions, but before that I wouldn't have dreamt of questioning a surgeon or anything 'cause you just think that's their job.". Consequently, she had stopped seeing her original surgeon and at the time of her interview, was under the care of another surgeon.

Besides being less open in matters related to her critical illness and future management, participant 12 was also less receptive to her friends, especially with regard to listening to their problems. She said, "I used to be interested in people and, you know my friends did tell me things and I'd give them advice and all that. Now I can't. 'Cause sometimes I just think 'Oh I don't want to hear'. I can't be bothered. And it's horrible, especially when it's your friends and they've always come to you for advice and now I just think 'Oh I wish they wouldn't, I can't be bothered listening to them'.".

Last but not least, a few survivors became less effective in their communication with others⁵³. Both participants 13 and 17 highlighted this. As participant 13 pointed out in his interview (extract presented earlier in this chapter, on Page 104), self-consciousness and anxiety about his stammer⁵⁴, with a vicious cycle between the two, interfered with his conversations with others. In participant 17's case, she got depressed after her critical illness, and consequently she found that her cognitive function deteriorated. She often struggled for words and could not put things in sequence when explaining things to people. She found herself giving up on conversations because it was too tiring to sustain a sensible dialogue with people. In fact, she had to tell one of the surgeons she was seeing that she was unable to give him the history he needed.

Other than these general trends (which occurred in at least two survivors who participated in the study), there were also some miscellaneous changes in survivors' interactions and relationships reflective of their emotional/psychological status, which were unique to the individual. For instance, as already mentioned, participant 11, who undertook a lot of avoidance strategies in her own life to try and steer clear of any emotional/psychological distress, also tried to get others to do the same. She would not let her daughter wear green because the colour green made her angry. She also would not let the critical care nurse following her up drive to her home because she was protective of this nurse and was worried that the nurse would get hurt when

⁵³ This has been covered alongside with other activities in the subsection on 'Activities and behaviours' but it is covered in more depth here because of its importance in the area of interactions and relationships.

⁵⁴ He had had a stammer before his illness, but it had got worse after his illness.

driving.

Another illustration was provided by participant 17. Being more aware of her own mortality, she was more considerate of her children and did quite a lot of things with her children in mind. For instance, she made a will, informed them of where all the important and relevant documents were, and made a start with clearing her home.

It was clear from this subsection that although there were some general trends in how survivors' interactions and relationships were modified by their emotional/psychological status, survivors were also distinctive from one another. There are some differences in the way survivors' emotional/psychological status influenced their interactions and relationships.

5.3.7. Other aspects of a survivor's personal status

A. Physical consequences

Survivors' emotional/psychological status sometimes gave rise to physical symptoms. Shortness of breath, sweating, palpitations, physical tremor and shaking, stammering, abnormal sensations (pain and discomfort, going hot and cold, felt skin crawl, etc) and nausea were all symptoms raised by participants of this study. Anxiety seemed to be the most common culprit for these symptoms although one survivor, participant 12, said that frustration was the cause of her excessive sweating.

B. Cognitive consequences

For some survivors, emotional/psychological factors had an effect on their cognitive status. Examples of such survivors were participants 13, 17 and 18. Participant 13 spoke about anxiety and racing thoughts causing a degree of confusion for him. With participants 17 and 18, depression led to cognitive dysfunction. Participant 17 found it a struggle to find words. In addition, it was difficult for her to think coherently, which, in turn, made it hard for her to form judgments and take decisions. As for participant 18, his thought processes slowed down and he found that his creativity decreased. He also could not concentrate and found it hard to make decisions.

5.4. Conclusion

The emotional/psychological status of survivors at between 6 months and 15 months after discharge from critical care varied widely. It varied between being relatively unaffected emotionally/psychologically to suffering such overwhelming and devastating emotional/psychological consequences that one survivor even asserted that her illness had "absolutely ruined her life". This is because the emotional/psychological status of any survivor is the product of a number of different

factors (these include their previous emotional/psychological status; their response to critical illness and its recovery, including the intensity of the response; the emotional/psychological support they have had/are having; their ability to recover or achieve an equilibrium point in their emotional/psychological status; and finally, the end point of recovery or equilibrium). All these contributing factors differed from survivor to survivor.

Although there were a few study participants who were very minimally affected by their critical illness and recovery experience from an emotional/psychological point of view, most study participants were affected emotionally/psychologically to some degree. Generally speaking, the overall impact was a negative one for the majority of survivors; critical care survivors tended to be, on the whole, emotionally/psychologically worse off than before their critical illness.

However, whilst emotional/psychological distress was far more common amongst study participants when compared to positive emotional/psychological responses, positive feelings and reactions could still occur at points during the experience.

In addition, besides emotional/psychological changes that were conceded by most to be either positive or negative, there were also changes that were not as readily classifiable. As highlighted earlier in this chapter, participant 10's outlook that she had been a second chance in life was an illuminating example of this. On the one hand, it gave her increased motivation to try new activities, while, on the other hand, she was also more easily frustrated with her husband because there were times when she perceived that he was wasting precious time which was part of her second chance at life.

Consistent with survivors' emotional/psychological status (widely differing, with the majority of survivors negatively affected in some way), the impact a survivor's emotional/psychological status had on his/her life also varied, with a predominantly negative influence. These effects could be spread over many areas, including, perception of, interpretation of, responses to life; personality; external appearance; activities and behaviours; physical zone of comfort and activity; interactions and relationships with others; and finally, other aspects of survivors' personal status. Unsurprisingly, there were survivors such as participants 11 and 24, who, because of emotional/psychological issues, were practically housebound with considerable limitations on their daily lives. For some of these survivors, the adverse effects of their emotional/psychological status could be somewhat reduced by contextual factors such

as support from others.

On the other hand, as in the case with survivors' emotional/psychological status, the lives of certain survivors underwent what they themselves saw as positive changes. For example, participant 25 spent less of her time cleaning and tidying her house because she was less obsessive about the state of her home. Although this was due to a lack of energy (and not having adequate energy was generally viewed as a negative thing), she saw her decreased fixation on keeping her home a certain way as a positive thing as shown by this excerpt, "...I used to have OCD⁵⁵ tendencies of having everything just so in the house, and that's gone, so that's a positive...I used to, kind of, have to Hoover the house every single day, not really bad OCD, but OCD tendencies, and everything had to be kind of square and just so and that's gone, so that's a positive."

All in all, although there were some exceptions, the changes brought about by a critical illness and recovery experience were generally perceived negatively by survivors when the changes pertained to their emotional/psychological status and the impact of this status on their lives. Nonetheless, there were positive emotional/psychological responses with some positive consequences stemming from them.

This concludes the findings on survivors' emotional/psychological status and its impact. The next chapter is on survivors' cognitive status and the impact that aspect of survivors' personal status has on them.

⁵⁵ Obsessive-compulsive disorder.

Chapter 6: Survivors' cognitive status and its impact

6.1. Introduction

This chapter concentrates on survivors' cognitive status and the effect this particular aspect of survivors' personal status has on them. The chapter first looks at the details of survivors' cognitive status before moving on to delineating its impact.

6.2. Description of survivors' cognitive status

As with survivors' physical and emotional/psychological statuses, the resultant cognitive status of study participants varied from one another and was dependent on a variety of factors. These include:

- Their previous cognitive status. It was clear from the interview data that different survivors started from different points. Participant 13 had pre-existing problems with forgetfulness which worsened after critical illness whereas participant 18 functioned fairly well before his illness as shown by the fact that he achieved one of the highest marks in his class for a piece of work done for his diploma course.
- The cognitive consequences of (i) the disease process(es) underlying the critical illness and (ii) the complications experienced by survivors during the course of the illness. For instance, strokes very often have cognitive repercussions.
- The impact critical illness itself can have on survivors' cognitive status. Being critically ill can adversely influence survivors' cognitive status in both direct and indirect ways. The reasons underlying the direct effects of critical illness on cognitive status are still poorly understood. However, it is unlikely to be due to a single cause but rather, secondary to multiple mechanisms interacting within individuals vulnerable to such insults (80, 106). Possible mechanisms include derangement of chemicals in the brain, biochemical derangement of the blood, brain injury, environmental factors as well as factors induced by the treatment processes (106). Indirectly, critical illness can affect cognitive status through its effects on survivors' physical and emotional/psychological statuses. For instance, participant 13's forgetfulness worsened with fatigue and participant 17 asserted that she noticed a link between her low mood and word finding difficulties. Medication that survivors have to take after critical illness may also play a role. For example, participant 12 felt that the morphine she was taking might be worsening her cognitive problems.
- Survivors' personal resilience in this area. This is essentially their intrinsic

capacity to regain cognitive health should it undergo an insult (This particular definition is modified and adapted from Herridge's definition of physical resilience and emotional/psychological resilience (105).). A number of study participants spoke about the 'natural' improvement of their cognitive problems over time. In addition, some survivors tried to help themselves by pushing themselves cognitively, for example through doing Scrabble puzzles or forcing themselves to learn new information.

In general, when an episode of critical illness had an impact on survivors' cognitive status, it caused a decline in their cognitive status (as opposed to improving it). The cognitive changes experienced by survivors are outlined in Table 6.1.

Table 6.1: Cognitive changes experienced by survivors

- Disorientation and confused state of mind.
- Memory issues:
 - Impaired recall and amnesia.
 - Forgetfulness and absentmindedness.
 - Disruption of procedural memory with increased cognitive exertion doing what was previously mentally effortless⁵⁶.
- Problems with attention and concentration.
- Executive dysfunction⁵⁷ with problems in many cognitive tasks. Examples include:
 - Difficulty completing tasks.
 - Difficulty multi-tasking.
 - Difficulty with reasoning and problem solving.
 - Difficulty with decision making.
 - Difficulty with judgment.
- Language issues:
 - Difficulty expressing oneself, such as word finding difficulties.
 - Mistakes in written form such as difficulty spelling words and separating words appropriately.
- Decreased visual-spatial awareness/abilities.
- Mental slowness.

Before moving on to the impact of this cognitive decline, there are three key points to emphasise. First, the different areas of cognitive status are not distinct and there is a certain degree of overlap and linkage between them. This overlap and linkage extends to the various cognitive changes seen in survivors. For instance, executive functions regulate a person's focus on the task at hand (attention and

⁵⁶ Survivors talked about having to think through things a lot more, even with respect to actions that came naturally to them previously. Examples included writing and performing DIY tasks (especially complex tasks requiring multitasking).

⁵⁷ Sheldon Horowitz, the Director of Professional services at the National Centre for Learning Disabilities, provides a good working definition for executive functioning. He says that it "involves activating, orchestrating, monitoring, evaluating and adapting different strategies to accomplish different tasks" and "requires the ability to analyse situations, plan and take action, focus and maintain attention, and adjust actions as needed to get the job done" 107.

Horowitz SH. Executive functioning and learning disabilities. 2007 [cited 2009 July 4th]; Available from: <http://www.ncld.org/ld-basics/ld-aamp-executive-functioning/basic-ef-facts/executive-functioning-and-learning-disabilities>. Executive dysfunction therefore refers to malfunctioning in these areas.

concentration), utilise working memory (which temporarily stores and processes information so that a task can be completed (108)) and facilitate recall of information. Therefore, a problem with these functions of executive control can ultimately give rise to what would be perceived as concentration and/or memory problems.

Another strong association is between the areas of memory and concentration; attention is involved in the encoding process of memory (109). Therefore, unsurprisingly, although participants attributed some of the challenges they faced to memory problems, their in-depth descriptions of what was happening revealed that there is a high possibility that impaired ability to concentrate is the root cause. This close relationship is also most likely the reason why the same example raised by survivors was labelled as a memory problem in one part of the interview and referred to as a lack of concentration in another part of the interview.

The final illustration is the connection between confusion and cognitive areas like attention/concentration and memory. Lacking concentration and starting multiple jobs at once can lead to a degree of confusion in the mind of survivors. Not being able to remember crucial pieces of information can also affect a person's ability to make sense of what they are doing or what is happening around them.

Second, when talking about the cognitive changes listed in Table 6.1, study participants often did not name the exact change, but rather, either described the change in a lengthy fashion or in terms of cognitive areas such as memory and concentration. For instance, when talking about a disruption in their procedural memory, participant 08 and 13 did not simply name their cognitive change as a disruption of procedural memory, instead, they described changes characteristic of this cognitive problem (which include losses of previously learned skills and the inability/decreased ability to learn new skills (110)). Both participants described vividly about how holding a pen did not come naturally to them anymore. Interviewee 08 talked about how she felt that she had to be re-taught how to hold a pen while interviewee 13 indicated that he had to focus and think particularly hard when he was writing. As another example, when it came to executive dysfunction, some study participants described problems indicative of this cognitive change, such as difficulty in multi-tasking, problem solving and making decisions, rather than simply say that they had executive dysfunction. Other participants spoke about their executive dysfunction in terms of cognitive areas such as memory and concentration, as seen in participant 25's case. She related her inability to multi-task to a problem with a problem with her short-term memory, as seen in this extract, "...my short-term

memory – I used to be able to multitask and hold things in. I have to just totally focus on the thing that I’m doing and if somebody distracts my attention at all, I can’t remember what I was doing...”.

The fact that study participants did not identify their cognitive changes directly (after all, cognitive status is a complicated field even for experts) mean that the accounts that could conceivably pertain to cognitive changes (i.e. examples, elaborations and explanations of their problems) were examined and dissected carefully, to ensure that all the cognitive areas that had been affected were captured. The list of cognitive changes given in Table 6.1 is a reflection of this process.

Third, in contrast to the situation with regard to survivors’ physical status and emotional/psychological status, the cognitive changes described by survivors appeared to be entirely secondary to their critical illness episode, with negligible influence from contextual factors. None of the interviewed survivors gave any concrete examples of contextual factors improving or worsening the cognitive changes that had occurred after their critical illness.

Now that the nature and noteworthy points of the cognitive changes have been highlighted, the next subsection focuses on the impact exerted by these changes.

6.3. Impact of survivors’ cognitive status

It is evident from the interview data that survivors’ cognitive status played an important role in their life; their cognitive status had considerable effects in many areas. The areas that could be affected are listed in Table 6.2.

Table 6.2: Areas that could be affected by a survivors’ cognitive status⁵⁸

- Perception of, interpretation of, and responses to life.
- Personality.
- Activities and behaviours:
 - Posture and mobility:
 - Personal posture and mobility.
 - Driving.
 - Sleep/rest.
 - Communication.
 - Self-care activities.
 - Activities associated with societal roles.
 - Other activities:

⁵⁸ The precise definitions for these areas and sub-areas are in Chapters 4 and 5.

- Recreational and leisure activities
- Social activities
- Physical zone of comfort and/or activity.
- Interactions and relationships with others.
- Other aspects of the survivor's personal status:
 - Physical consequences
 - Emotional/psychological consequences

Again, as in the case when the impact of emotional/psychological status is being discussed, the general points highlighted about the effects of survivors' physical status are also applicable here.

These points, put in the particular context of cognitive status and its effects, are as follows:

- The actual impact experienced by survivors was the end product of how survivors' cognitive status was interacting with the context of survivors. In other words, the consequences described did not stem simply from survivors' cognitive status alone. The role that contextual factors played is discussed in further depth in Chapter 7 of the thesis. In this chapter, their role is simply highlighted whenever relevant.
- The aim had been to be as comprehensive as possible when describing the impact of survivors' cognitive status in relation to their QoL. Therefore, the degree of relevance of each effect described varied from survivor to survivor.
- The effects were not as circumscribed as the areas and sub-areas listed in Table 6.2. Many of the effects in one area resulted in secondary effects in other areas. To prevent the discussion from becoming overly difficult to follow, these knock on effects and the specific links between various areas are not always discussed. In addition, it is not crucial to the study goals that they are fully described. However, it is good to be aware that they exist.

With these points in mind, the effects in each of these areas listed in Table 6.2 are now examined in turn.

6.3.1. Perception of, interpretation of, and responses to life

Of the cognitive changes survivors suffered from, amnesia, in particular, had an impact on this area. As a result of not remembering the critical illness, a number of survivors were unprepared and less accepting of not being able to carry on life as

before.

For instance, participant 10, who had been preparing for a trip overseas when she became ill, came round from her critical illness and wanted to go on the trip. It was almost as if she could not grasp the fact that she had been ill and expected to carry on life as usual. She recounted this during her interview, "I remember saying to him, "Seeing as I'm here and I've got a bit of time I'll do a bit of packing for Saturday," to go to ***** [country she was going to]....And I picked a green cardigan out of the wardrobe, and I thought, "Oh yeah, I've only wore that a couple of times, I'll make an outfit like that; that's decent." And I don't remember anything after that till the 4th of February...And then, as I say, the next thing, I came round on the 4th of February...I said to her [participant's daughter], "What day is it?" And I can't remember what day it was! I haven't the faintest idea. And I said, "Oh right." "Oh, what date is it?" So she said, "Why? What do you want to know for?" I said, "Because I've got to go to ***** [country she was going to]." So she said, "Mother, it's the 4th of February..." And I looked at her and I said, "But I want to go to *****." She said, "Well, you can't go. And that's that. And there's nothing you can do about it." I said, "What date is it?" And she said, that's when she said to me, "It's the 4th of February...." And I said, "Well, what did I do for Christmas and New Year?" She said, "You were here." "But I want to go to ***** [country she was going to]." She said, "Well it'll have to wait. Now shut up," she said, and all I said, my daughter in law was with her, and apparently all I said that visiting time was, "I don't care what day it is, what time it is, I want to go to ***** [country she was going to].".

Participant 10 also talked about how amnesia of her illness meant that she did not realise how ill she had been. She could not understand why she could not do what she used to be able to do and got frustrated with herself. She put it like this, "I get annoyed with myself because I can't do things and I think I should be doing this and I think I should be doing that, and they say, "Well Mum, you don't realise how ill you were.""

Participant 12 was similarly affected. When asked whether her amnesia of the events surrounding her illness affected her, she said, "I think it did to me getting better because I thought I could just come out the hospital and I'd be fine in two or three weeks time...I think that's 'cause I just didn't realise how ill I was. I really did think I don't know what they're giving me a wheelchair for and everything, I won't need that. I didn't realise, at all, I just didn't. I didn't realise how weak I was and how much it

had took out of me.". She clearly did not totally understand how sick she had been, and thus, did not fully grasp the extent of her limitations.

6.3.2. Personality

There is evidence from the study data to suggest that amnesia of the events surrounding the illness, if not rectified, could lead to a change in personality. Participant 24 was the study participant who described this most vividly. She had been unable to remember a lot of what had happened. In addition, she had not had the follow-up she needed to get the necessary information.

In her words, "I don't remember my mum, like I believe-- my mum and dad, I believe, had phoned me on the morning and couldn't get contact. The day before that, I picked my sister up from ***** Airport. Now I don't remember travelling to ***** Airport. I drove, with my children in the car, and I do not remember that journey whatsoever. And that's the scary part, because I could have killed me and my children in that car that night. That's another thing that I'm dead scared about, 'cos I can't remember and that worries me and scares me, the fact that, where did them two days go, apart from the other nine days that I was sedated. So I feel like in myself I've lost nearly three weeks of my life and I can't get it back and I can't get the answers that I'm looking for, because nobody really knows apart from them nurses, doctors...I think that's one thing that scares me a lot, because, like I say, it's three weeks of my life I don't remember, and it was the worst three weeks of my children's life that I can't give them answers for neither, and I find that very difficult, really hard...I just need answers, and I think these questions could have been answered if somebody had, as I said, took the time out and seen me afterwards instead of leaving it for like six months now, if not longer. And I've got myself this way because I haven't had the answers. And instead of it turning out to be three weeks I've lost, I'm losing nearly like a year. It will be by the time-- if I do speak to somebody. Because I can't move on, just can't seem to get past this."

Consequently, like she said in the extract (and repeatedly said throughout her interview), she had had many unanswered questions about the events surrounding her illness, with no way of making sense of what had happened to her. This constituted at least part of the reason for her emotional/psychological distress after her illness, which in turn had led to a change in her personality. As she said, "It's changed me, my personality, it's changed everything. And that's why I need closure to all of it, because I need to be able to move on, get rid of these feelings, get some answers.". Undoubtedly, the amnesia about her illness, alongside a lack of information to fill in

the gaps, had had a part to play in the profound impact critical illness had on her, including the effect it had on her personality.

6.3.3. Activities and behaviours

The cognitive changes experienced by study participants interfered with their activities and behaviours. The cognitive change of amnesia had slightly different implications for this area compared to the other cognitive changes. Therefore, the effects of this particular cognitive change and those of the other cognitive changes are dealt with separately, in turn.

A. Activities and behaviours affected by amnesia

Among the study participants interviewed, amnesia appeared to exert an effect on only two sub-areas of activities and behaviours, namely, sleep and sexual activity. The other sub-areas of activities and behaviours did not seem to have been affected.

I. Sleep

As already stated, participant 24 was a survivor who had had fairly marked amnesia of the events surrounding her critical illness. Unsurprisingly, she harboured many questions about that period of her life, most of which had remained unanswered because she had not been getting the information she needed to fill in the necessary gaps. Due to the fact that she had not been able to get the answers she needed, she was left constantly ruminating over her illness, including what had happened, why it had happened and whether it would happen again, especially at night. These ruminations (together with her nightmares) disrupted her sleep and kept her awake. Like she said, "I think that's probably why I don't sleep much as well, like every night, because it seems to all come back to me every night really. It's very quiet on my own, in my room, kids asleep and there's no-one else there and you lie there and you think - and it's always the same thing that I think about, just like how ill I was and not waking up and just questions I need answering and things like that."

II. Sexual activity

Survivors' amnesia could also interfere with their sexual activity. For instance, when participant 23 was asked why she felt that she did not know her partner anymore after her critical illness, she asserted that she could no longer remember how close she had been to him, and thus, felt emotionally distant from him. As a result, she did not want to be physically intimate with him.

B. Activities and behaviours affected by cognitive changes other than amnesia

According to the study participants, the other cognitive changes listed in Table 6.1 also had an impact on their activities and behaviours. The effects are in the

following sub-areas of activities and behaviours:

- Posture and mobility:
 - Personal posture and mobility.
 - Driving.
- Communication with others.
- Self-care activities.
- Activities associated with societal roles.
- Other activities:
 - Recreational and leisure activities.
 - Social activities.

In terms of how cognitive changes (other than amnesia) affect the abovementioned sub-areas of activities and behaviours, many participants had been/were unable to perform many of the abovementioned sub-areas of activities and behaviours in a smooth fashion, the way they had had been able to do before their illness. In general, the restrictions include:

- The inability to carry out a task to completion. For instance, participant 10 spoke about going to the kitchen to do a certain task, like bringing the laundry in, but getting distracted with another task like washing the dishes and ultimately not bringing the laundry in.
- Encountering many inconveniences resulting from their poor cognitive status as they went about their activities. As an example, participant 25 locked the keys in her car numerous times. She had also lost quite a few mobile phones.
- The inability to multi-task in the way they had been used to. As some study participants pointed out, juggling several tasks at the same time was what they had done on a daily basis, especially when certain activities called for them to do so. Consequent to their cognitive changes, they had been unable to multitask in the same way, which had interfered with them carrying out their activities in their usual way. As a case in point, participant 13 said, “I found that a real toil at first was actually getting to the toilet, and keeping myself clean and dressing myself, I really struggled with. I couldn’t, and I still can’t stand up now to put me trousers on. I have to sit down and the same with my shoes whereas before I’d be running round like, pulling my trousers up, tying my tie at the same time, getting my shoes on, I just can’t do that...when I’m in the front of a car, going anywhere, I can’t take in everything around me and process it like I could before, and like street signs, I’ll miss things and

cars...really I can't see myself, you know coordinating everything like the gears and the clutch and being aware of it. It's too much for me to take in at the moment.". Another participant thus affected was participant 25. This was a short extract from her interview, "I used to be able to multi-task and hold things in. I have to just totally focus on the thing that I'm doing and if somebody distracts my attention at all, I can't remember what I was doing."

With such restrictions, survivors sometimes stopped doing the activity or at least delayed doing it. For example, participant 13 started taking a course. However, after three weeks of struggling, he realised that his cognitive problems were preventing him from learning the new material and applying it. He therefore stopped taking the course.

Another way that survivors dealt with these restrictions was to develop ways of getting around the restrictions, with or without using contextual factors such as tools and aids or support from others. For instance, some survivors gave themselves time to take things slowly. Participant 25 was a survivor who used this strategy a lot. This was what she said, "...And memory things, you know, I've made constant adjustments for and learned avoidance strategies and all sorts at work to deal with—Like if somebody asks me something on the hop that I should be able to recall, I always go, "I'm desperate for the loo, can I get back to you in a minute?" and go away and have a little think. And there's some students in and we're supposed to be writing a final assessment for them, and I just assumed that the tutor would give us the forms to take away to fill out. She wants it doing on the spot. Oh I can't do it on the spot. I can't recall. But I can't say to her, "I can't actually recall, you know, the phrases I'm—" So I said, "I'm really sorry. I've got a lunchtime appointment at the doctor's." ...I said, "I'll have to email you it tomorrow." Just all those things that you just think and do, to stop yourself looking incompetent and stupid.". Other coping strategies included having a set routine, recurrent checking behaviours, writing things down and/or using lists as reminders, and relying on other people to help.

In contrast, there were also times when survivors persisted with doing things the same way they had done before their illness. They generally ended up experiencing continuing problems. For example, participant 24 talked about putting something on to cook, forgetting about it and ending up with the house full of smoke.

Having discussed the effects of cognitive changes (other than amnesia) in this area in a general fashion, the rest of the subsection concentrates on exploring some of the specifics within each sub-area of activities and behaviours.

I. Posture and mobility

Both personal posture and mobility and driving were affected. Where personal posture and mobility is concerned, the aspects that appeared to have been particularly influenced included walking, hand grip and hand dexterity. With regard to walking, study participants spoke about bumping into objects more frequently, as demonstrated by the following extract from participant 13's interview data: "...it's like my spatial awareness has changed, as bizarre as that sounds. I used to be very conscious of what was around me, but I'm forever banging my legs on things, you know, things like door handles sticking out or walking past somebody's basket in the supermarket and 'bang' against my leg. I permanently have bruises on my legs from where I'm banging them."

When it comes to hand grip and hand dexterity, participants complained about not being able to do these activities as effortlessly as before. Using participant 13 again as an example, he said, "I find it very difficult. Especially if I'm doing something that requires a lot of dexterity. Like...let's say...example, I make noise effects for the train sets. And it involves soldering components onto a circuit board. I really struggle. I really, really struggle with it. Whereas before I could just solder things up. You know, no problem at all...After using tools all my working life I still struggle now with screwdrivers and you know, a lot of things that I used to use my hands for, I do struggle...playing my guitar. I find that really difficult. Writing. Very poor at writing now. My writing's gone like quite shaky. Because when I'm trying to focus and write at the same time, it doesn't come natural now. I have to really like concentrate on what I'm doing and the more I find I concentrate on it, the worse it gets, because I'm thinking about it too much. Like a lot of things just don't come naturally. Whereas they used to do."

As for driving, study participants experienced a few different kinds of problems, depending on what the cognitive change had been/was. For instance, participant 25 had memory problems. Although this did not interfere with her driving per se, her poor memory meant that she kept locking her keys in the car. On the occasions that happened, the whole process of driving a car was disrupted.

Participant 05 had a different problem; for him, his inability/decreased ability to drive stemmed from poor concentration. As he said, "One of the jobs I used to do, I used to drive and I used to like that. Keeping my concentration long enough for driving is difficult... I used to do some runs down to ***** and ***** ***** in a large transit van for a company I worked for and I'm just thinking about making that journey

now and thinking, oh God no, I don't want to do it. Pain is one thing...most importantly for that job is the concentration. You have to keep your mind on the job all the way there. Now I can't, I can't manage to keep my full attention on the television for a whole programme so, no, I won't be doing that job...".

As for participant 13, he was unable to drive because his cognitive status was such that he could not multitask⁵⁹; as he said, he would not be able to manage the clutch and the gears alongside looking at road signs and watching other cars.

II. Communication with others

For a number of study participants, their cognitive status affected their communication with others. The ways survivors' communication could be affected included the following:

- A couple of survivors, like participant 19, highlighted how they would forget to make the phone calls they needed to make. As participant 19 said, "...my friend keeps on phoning me and I'll say I'll call her back and then by the time I remember I'm going to call her back, it's half past ten and I'm thinking, "Well, no. I can't phone, it's too late.""'. They would also forget what they have told people.
- They were less effective in expressing themselves. Examples of such survivors included participant 07, 17 and 23; they had difficulty concentrating on the conversation and finding the appropriate words. Participant 07 put it in this way, "...concentration was another thing, concentration was appalling. I could be talking to you and drift off and forget what I was saying, just come to like going to make a sentence and, and forget the end of it...sometimes I'm going to say something and I can't think of the word I want...Not so much now but at first it was awful...I knew the word I wanted to say but it just wouldn't come, and that's since I've come out of intensive care. As I say, it's not so much now but at first I would be flustered and thinking, oh, what did I want to say? But now it's just occasionally, it's just the word that just won't come to me.".
- Survivors also had problems when they were at the receiving end of the conversation. They found it hard to listen to others. As participant 11 said, "Concentration was minimal...I didn't want people to talk to me, because after a while, a short while, I'd just wander off into my own little world anyway and

⁵⁹ The extract demonstrating that has already been presented at the beginning of Section 6.3.3.B and would not be repeated here.

I wouldn't really know what they were talking about. So people could be talking to me and I could be looking at them and really not concentrating on a thing they were saying, and I could never repeat the conversation." As she aptly pointed out, survivors also had problems remembering what was being said to them. However, for some survivors, it was not that they did not take in and hence, could not remember what was being said to them there and then (like in participant 11's case), but that they often forgot, at a later stage, what people had told them.

- Due to the above problems with communication, some survivors reduced how much they communicated with others.

For survivors such as participant 13 and 23, many of the above communication problems improved when communicating with people they were more familiar with, or even just when someone they were close to was around. This was chiefly due to the fact that the familiarity provided some reassurance, thus reducing the nervousness they were experiencing consequent to their poor(er) cognitive status.

III. Self-care activities

In some study participants, their cognitive status influenced their ability to carry out self-care activities. Certain self-care activities seemed to be more affected than others. Dressing is one such activity, as seen in participant 13's case. He spoke about having difficulty dressing in the same way as he had done before his illness⁶⁰; he was unable to multi-task and carry out activities in relation to his dressing the way he had done before. Another self-care activity which was affected by survivors' cognitive status pertains to them looking after their own health, such as remembering to attend their medical appointments. For example, participant 12's husband had to keep a diary of her appointments or she would forget to go. Similarly, participant 11 also needed reminders to keep her appointments; in her case, she was reliant on others prompting her.

IV. Activities associated with societal roles

For several survivors, their cognitive status had a significant impact on their activities associated with societal roles. The types of activities associated with societal roles affected included domestic chores and activities, work and learning activities.

⁶⁰ The excerpt highlighting this has already been presented at the beginning of Section 6.3.3.B.

Unsurprisingly, if a particular activity in this sub-area calls for a considerable level of cognitive ability, it is more likely to be affected. For instance, participant 17 had problems dealing with administrative paperwork. As she said, "...it also meant that mail, you know letters and things, or other documentation were coming in through the post and I'd just check what they are and put it on the pile. So things were piling up literally. Yes, I just couldn't deal with, couldn't think about it. Certainly couldn't make any decisions and think what was the best thing to do. Just couldn't stay focused. So, I have, I mean, I've got another pile at the moment, in the hall waiting for me. It's that time of the year when everything comes, you know at the end of the financial year. I have gone back to quite a few things that needed dealing with and, well, I managed to find enough brain power to get on with it. But it's very difficult...It's very hard to focus indeed to think clearly and coherently...the thinking process would be disrupted even to the point of I would say some thought disorder...I mean the ability to think through, as I say, even minor problems you know, you have to think to be able to work out a solution so that you can do whatever task is in front of you, I found I couldn't do that, I couldn't...sequencing was difficult, that for one thing, I'd forgotten how to go about things..."

In addition, participant 13 struggled with learning activities and participant 25 had significant difficulty carrying out her job as a teacher. Participant 13 signed up to do a counselling course, but his poor memory and concentration meant that he had to defer the course. As he said, "I've got a very short concentration span...at first I could read for a minute and then the lines would be all over the place⁶¹ and I'd have to go back and read it because I'd forgotten what I'd just read. And I actually signed up to do a college course. I was going to do an introductory to counselling...I went for three of the lectures and it screwed me up. Because what the lecturer was saying and what we were reading, two minutes after I had completely forgotten. And I'd have a question on that and I couldn't remember what the answer was. And then I'd go back and I couldn't remember what the question was. And I was just going round in a circle. And within three weeks I was three weeks' behind in the work...I was coming home worrying about that...So I deferred it until next year."

As for participant 25, she could not do her work like she had done before her illness, and had had to develop strategies to get around the restrictions she had been experiencing at work. The following excerpt contains some of the things she had said

⁶¹ He had problems with his eyesight too, and that also constituted part of his struggle with reading.

about her work: "Well, work's hard. I had to go back after six months 'cause of financial reasons and I really wasn't in a state to go back. I struggle at work because I can't remember things. 'Cause I teach, I can't pull words out of--, if I'm going to explain something, the words just aren't there and people ask me stuff that I used to be able to just recall straightaway and I have to go, "Well, I'm thinking,"...It's like trying to write reports and I used to be able to click things out of my head about kids and just knew them inside out and I'm having to go and get all my records and get their books and so they're taking me like 100 times longer...I have to have a place for absolutely everything and I've written down where everything is...I used to be able to just go like that with the planning sheet and then deliver the lesson and now, I always like have to up and down, you know, just as a reminder or I have little prompter cards on the side so it doesn't interfere with the lesson, stuff like that, and it is wearying."

Having said that, the cognitive status of survivors may be such that even a relatively simple task like completing the task of bringing the laundry in is a problem for them. This was seen in participant 10's case. As she said, "...sometimes now my memory can wander. I'll say now, "Oh I'll go and bring the washing in." And I'll go to the kitchen and perhaps there's a cup and saucer or something in the washing-up bowl. The washing's calmly blowing on the line; I'll wash the cup and saucer, then come back in here. He'll go in the kitchen to put the kettle on or something and say, "Do you realise it's raining and the washing's out?" "Didn't I bring it in?" "No." "Oh I thought I'd brought it in a bit ago...". She would also forget what she needed to get when shopping, as she said in this extract," Or he'd take me shopping and I'd make a list before I went to the shops, and nine times out of ten the list was here and I was in the shop. And he used to say, "Well what did you come for?" "Mm." And then I used to think, "Well we use this, or we use that, or we use the other." So at one point I had nine very large tins of Bisto because I thought, "Well, if it isn't that I've come for, it's something I'll use." And another point it was teabags. But it probably wasn't that I was going for: it'd probably be oil or washing-up liquid or, you know. But if I saw something I'd used, I used to say, "Oh we'll have that," to make it look as if, yes, I knew what I was coming for. "What have we bought another thing of Bisto for? We've got so many here!"".

V. Other activities

a. Recreational and leisure activities

Certain recreational and leisure activities such as reading, knitting, watching TV and doing puzzles all require a certain level of cognitive competency. Therefore,

as to be expected, some participants' recreational and leisure activities had been/were affected by their cognitive decline. Like participant 05 said, "...when I first came out of the hospital, concentrating on anything was impossible. My wife brought me some books into the hospital; Sodoku, I used to do lots of puzzles at one time and I couldn't even pick them up. Holding the book was difficult, reading it, my eyes, eyesight was blurred. I couldn't see to the end of the ward and that continued as I came home and to be able to do a crossword was impossible; read an article in the paper, impossible. I used to watch the telly. I watched a lot of documentaries; I don't like these rubbishy soaps and things like that. I've just been watching one, 'Power of the Earth', Dr. A. A. Stewart, that's about volcanoes. All those sort of documentaries I'll watch. When I first came out of hospital, I couldn't concentrate at all, I could sit in front of it and not take anything in for an entire hour. Now I've improved on that. I don't take it all in by any means, but it has greatly improved. I can actually enjoy a documentary reasonably well. But I have to watch it again because I miss most of it. My concentration wanes.". Similarly, participant 10 was initially not able to knit because she could not concentrate long enough to do so.

b. Social activities

The cognitive changes experienced by participants could also interfere with their social activities, particularly those that involved communication quite heavily, such as chatting on the phone. This was because survivors tended to be very conscious of the fact that their cognitive status was interfering with their communication, and consequently, would want to cut such activities short. Participant 23 described this very well in the following excerpt: "I know I can't talk as good as I used to, sort of I'll get mixed up...Like T***'s mum wanted to say hiya to me last night and I said to ask for T*** and then she come on the phone and I couldn't talk...you can tell you are not as quick as you used to be, you're slower. People might be seeing you as slower and you don't want people to think that you're damaged, even though the professor said I am. And that I know I am 'cause I can't even hold a conversation, and then I start feeling all nervous and then I won't know what I'm talking about and then that makes me even worse and I just wanna go, "Ta-ra," because I can't talk what I'm thinking.". Participant 23 also spoke about how things were better for her when her long term partner was around, which meant that she was less apt to cutting her conversation short and stepping away from the social activity.

6.3.4. Physical zone of comfort and/or activity

For most participants, their cognitive status did not significantly affect the physical zone they were comfortable in and could freely move around in. However, for one particular survivor, participant 23, her cognitive status was such that she had problems finding her way home. Although she had other issues preventing her from going out, the fact that she had got lost while being out and about played a role in her being not as comfortable going out and about. As she said, "I can't go out like I used to. I can't go shopping and I'm like a recluse, in the house. I've tried to go over to me mum's once, and I had a really bad fall. I've been out and got lost in the streets, I've had to knock and say "I don't know where I live"". From this survivor's example, it can be seen that poor cognitive status in survivors could play a part in restricting their physical zone of comfort and activity. Of course, survivors might also try and reduce its impact. For participant 23, she tried to circumvent her problem by arranging for her partner to meet her.

6.3.5. Interactions and relationships with others

Survivors' cognitive status affected their interactions and relationships with others, particularly the nature and/or quality of these interactions and relationships. Interactions from the initial meeting with someone to more in depth and intimate relationships were all affected.

First, survivors did not function as effectively in their relationships as they had done before. One affected element was their ability to pick up clues and form opinions and judgments about people. Participant 12 highlighted this. As she said, "I was really sharp and--. Do you know like I could tell somebody by, after I'd sat and spoke to someone for a bit, I knew right away whether I liked them or not and I could tell what their nature was like and everything, I don't do that anymore."

Several survivors were also unable to remember information about the people they knew. Birthdays, names and phone numbers were among the things that survivors were unable to recall.

Another aspect that survivors were not as effective in as they used to be was their communication with other people (this has already been covered in detail in Section 6.3.3.B, Subsection II). In brief:

- Some participants, such as participant 19, forgot about the communication they had to do. They would also forget what they have said.
- They were less effective in expressing themselves. They would forget what they want to say. In some cases, survivors were also unable to find the words

they wanted, and thus, found it very difficult to convey what they wanted to say.

- A number of participants had problems when others spoke to them. They found it hard to listen to others. They also had problems remembering what was said to them; for survivors like participant 11, they could not take in what was being said and hence, could not remember what was being said to them there and then, while other survivors often forgot what people had told them only at a later stage.
- Some survivors reduced how much they communicated with others, largely due to the above three problems.

Second, specifically due to impaired recall and amnesia, survivors' sense of inclusion and closeness to others (both emotional and physical) could decrease. Participant 23 was badly affected in this way. She talked about how, "It's like you've walked into a party or a room and they've all been there all day, or what have you, and then you walk in and everyone in the room is going, "Oh this happened before" "That happened before", or "They've said this". You're getting little snippets from all different people and even though you might have been there, or you wasn't there, but now you know you are there you've gotta just take all their word, so you get a bit of a memory of it.". She felt that the other people in her life who remembered the events of critical illness could interact amongst themselves. For her, although she had been there, she had no memory of it, did not feel part of it, and could not contribute anything to the discussion. This made her feel like an outsider. In addition, she could not remember the feelings she had for her partner, and felt that she did not know him. Emotionally, she felt remote from him and consequently, she was not physically intimate with him.

Third, the amount of disagreement and conflict increased in some relationships. Participant 11 explicitly said that she argued with her partner because her memories did not coincide with his. In addition, certain survivors such as participants 12, 13, 19, 22 and 25, because of their poor memory, often disagreed with their family and friends about what had been told to them and occasionally on what they had said. Although such survivors did not explicitly talk about outright conflicts, the fact remained that a degree of disagreement existed within their relationships.

Fourth, the degree of reliance survivors had on others increased. For example, several of the survivors in this study had to rely on other people to fill in the gaps in

their memory. Participants 05, 08, 10, 15, 19 and 23 were all examples of such survivors. Other survivors needed help with remembering crucial information and reminders with performing certain activities. Participant 10 and 23 talked about how other people had had to remind them of birthdays. Participants 11, 12 and 13 all relied on others to help them with activities like medications and attending appointments (both medical and non medical related). Consequently, in certain cases, like participant 10's, there was even a reversal of roles. Before her critical illness, participant 10 used to be the one whom other people depended on for reminders. She said, "...the children and family members used to call me 'the elephant' cos they said, 'The elephant never forgets.' And they used to ring me and say, '****, whose birthday is it?' '**** this, **** that,' you know what I mean. And they used to--, they'd ring me up and say, '****, I've got an appointment at the hospital in three months. Give us a ring nearer the date in case I forget, will you?'" After her critical illness, other people had to remind her of dates like birthdays.

Fifth, a number of survivors were reluctant to let others know of their cognitive changes and/or took measures to conceal them. Participant 11 specifically highlighted the fact that she was not being forthcoming with information. Moreover, for some survivors, part of their interactions with others involved strategies to cover up these cognitive changes. Participant 23 talked about how she often wanted to end the conversation early because she could not express what she was thinking. Participant 25 made excuses to other people to buy time for herself whenever her poor cognitive status prevented her from doing what others wanted her to do. For example, she would say that she needed to go to the toilet or even that she had a doctor's appointment just so that she could get back to them later.

Last but not least, for certain survivors, their poor cognitive status affected how the people around them interacted with them. Participant 25's partner exploited her memory issues and used to tell her that she had not told him relevant messages even when she had done so. She, therefore, had to resort to writing down what she had said to him to avoid his continual abuse of this gap in her recall.

6.3.6. Other aspects of a survivor's personal status

A. Physical consequences

Although study participants did not indicate that their cognitive status had big effects on their physical status, there was undoubtedly still a degree of influence.

First, the physical fatigue experienced by survivors was sometimes a result of their cognitive status. For instance, participant 13, who had a short attention span,

often started multiple jobs at once. Consequently, this led to him feeling exhausted. As he said, "At times where I'll start off doing something and before I realise it, I'm doing five different things. I'll be in here, say, like tidying up, I'll be in the kitchen washing the dishes, I'll be upstairs sorting out the laundry, I'll be up in the loft sorting out the boys' room and, and I've got like five jobs going on at once and I can't remember what I've been doing last...a lot of the time when I've been like in a manic mood as I call it, I just end up absolutely exhausted and really run down and just feeling generally unwell a lot of the time."

Second, frequent bruising could occur. Survivors such as participant 13 were constantly walking into things due to poor spatial awareness. Hence, such survivors often had bruises.

Finally, survivors' cognitive status could result in them being unable to follow medical instructions (such as forgetting to take medication or forgetting to attend follow-up appointments), thus adversely affecting their physical status. Although at the time of interview, all the survivors in the study seemed to be able to carry out the medical instructions given to them, or at least had developed strategies to help them to do so, some survivors did say that they had neglected to comply with medical instructions at some point, such as forgetting to take their medication. If such situations had continued for any length of time, their physical status could well be adversely affected.

B. Emotional/psychological consequences

The cognitive changes experienced by survivors sometimes had emotional/psychological implications. For some survivors, their cognitive status caused marked emotional/psychological distress, even up to the point of depression. For instance, impaired recall and amnesia caused significant anguish in a number of survivors. Participant 24 even admitted to feeling depressed because of the amnesia surrounding the critical illness events. Although some survivors did not mind not remembering, participant 24 was one of the survivors who wanted to be filled in on what she had forgotten. Her personal situation was such that she had discharged herself, and hence, she had not had as many of the events filled in as others. She constantly ruminated over what had happened, and consequently felt very depressed that she had so many unanswered questions. Participant 23 was another survivor who felt very depressed because of her cognitive status. Having to work so hard at activities like sustaining a sensible conversation because of her mental slowness and poor memory caused her to feel very down.

A response related to sadness and depression was feeling demoralised. Participant 17 said, "I've always, you know, if things have been difficult, I've always looked for a solution and found it and problem solving has been my strength really and I've felt for a lot of the time since being ill, I've felt defeated, absolutely defeated, you know, overwhelmed, which is not the me that I was.". Being unable to do what she used to be able to do clearly left her feeling very dejected.

In addition, a number of survivors were very frustrated with their cognitive deficits and the problems they caused. The following two extracts demonstrated this well.

Participant 13:

"Yeah, the memory loss, it can be frustrating. That can be very frustrating. I'll make myself a cup of tea and forget I've done it, forget where I've put it. Forget where I've put my keys. Forget where I've put my phone. Go out and forget to take my wallet with me. Just all, having to check things, have I locked the front door? Coming back down stairs, check. Go back up. Did I lock the back door? Back down and check and that's frustrating. It drives me mad at times. Especially when I'm going out somewhere and it'd be, like, I can't find my keys, can't find my wallet, can't find this, can't find that. Yeah, I do find that frustrating."

Participant 25:

"I mean five times I've locked the keys in the car. And that's five times when I haven't had a spare with me 'cause then I started carrying a spare in my handbag...Then, about a week after that, I went to the loo in McDonalds and I always put my handbag on the back of the door and I completely forgot I'd put it on the back of the door and walked away without it, so it was stolen. You know, it's those kind of things that are really frustrating on a day to day basis."

Another negative emotional/psychological change secondary to cognitive decline was increased self-consciousness. As participant 23 had said (full extract in Section 6.3.3.B, Subsection V.b on Page 143), she was very aware of the fact that her cognitive decline was such that she "can't even hold a conversation". This would make her very nervous when talking to people.

Anxiety and panic attacks could also be a problem for survivors because of their cognitive status. Participant 13 recounted during his interview that his struggles

with learning material for his counselling course had led to marked worry and anxiety, even panic attacks (full extract on Section 6.3.3.B Subsection IV on Page 141). Another illustration was participant 10. She was very worried that she was getting Alzheimer's dementia when she became aware of her poor memory after critical illness.

The last of the negative emotional/psychological effects exerted by cognitive decline was already mentioned under Section 7.3.5 on 'Interactions and relationships with others'. Impaired recall and amnesia left participant 23 feeling like an outsider and emotionally distant from her family and friends. The details of this had been covered earlier and will not be repeated.

Not all the emotional/psychological consequences of survivors' cognitive status were negative ones. For instance, for some of the survivors who suffered from impaired recall and amnesia, they actually felt grateful, especially in cases when the amnesia was limited to the events that had occurred while they were critically ill.

6.4. Conclusion

Cognitive decline occurred in many study participants although it was by no means universal. Consequently, survivors' cognitive status could vary significantly. On the one hand, they could be relatively unaffected cognitively compared to what they had been like before their illness and also when compared to other individuals of their age and sex. On the other hand, they could have fairly marked cognitive deficits. This variation stems mainly from the fact that survivors' resultant cognitive status is contingent on a number of factors such as: survivors' previous cognitive status; the cognitive consequences of any disease processes occurring in survivors; the impact of severe illness on their cognitive status; and finally, survivors' personal resilience in the area.

As for the effects exerted by survivors' cognitive status, they were spread over many areas including:

- Perception of, interpretation of, and responses to life.
- Personality.
- Activities and behaviours.
- Physical zone of comfort and/or activity.
- Interactions and relationships with others.
- Other aspects of a survivor's personal status, including their physical status and emotional/psychological status.

The consequences in these areas were largely negative although survivors could

lessen their impact with appropriate coping strategies. Contextual factors could also help.

This completes my review of survivors' cognitive status and its impact. This chapter is also the final segment of the discussion on the impact of critical illness on survivors' personal status and their lives. In considering the impact of critical illness on survivors' status and their lives, this chapter and the preceding two chapters, Chapters 4 and 5, have delineated the various domains and sub-domains that need to be captured within a conceptual framework for survivors' HRQoL.

However, before constructing and describing this framework in detail, I want to review the role of contextual and personal factors in the concept of survivors' HRQoL. The interview data has highlighted that contextual and personal factors help shape and define the impact that an episode of critical illness ultimately has on survivors' HRQoL. Thus, it is important to consider the effects of such factors and explore how they might relate to an eventual conceptual framework for survivors' HRQoL. These areas are the focus of the next chapter.

Chapter 7: The role of contextual and personal factors

7.1. Introduction

From the interview data, it is clear that survivors' physical, emotional/psychological and cognitive statuses and the impact of these three aspects of their personal status contribute to the concept of HRQoL from their perspective. However, the data also indicate that contextual and personal factors have some influence over survivors' HRQoL. Contextual factors affect survivors' HRQoL by helping to determine the ultimate impact of critical illness on survivors' personal status and their lives. As for personal factors, they influence survivors' HRQoL by affecting their perception of the changes that have been/are occurring after critical illness.

This chapter discusses, in detail, how contextual and personal factors influence survivors' HRQoL and considers how they might relate to an eventual conceptual framework for survivors' HRQoL. Contextual factors are explored first, followed by personal factors.

7.2. Contextual factors

Both the context in which the illness occurred and the context surrounding the consequences of critical illness have an important part to play when it comes to survivors' HRQoL. In this section, their role is explored in turn.

7.2.1. Contextual backdrop of critical illness

The contextual backdrop of the critical illness encompasses everything to do with survivors and their lives before their illness (lifestyle, relationships, homes, etc). From survivors' narratives, it is clear that this backdrop defined the importance of their personal status in their lives and determined how vulnerable survivors' lives were to the effects of critical illness. In doing so, it helps delineate the exact consequences of critical illness and thus, plays a crucial role in the concept of HRQoL.

Participant 02's and 18's interview data illustrate how contextual backdrop helps define the importance of survivors' personal status. Participant 02's life was very dependent on his physical status. His personal posture and mobility, recreational and leisure activities, domestic chores and work were all very much tied to his physical status. Even his place of residence was somewhat dependent on his physical status because it was tied to his job. In contrast, participant 18's life was less physical. Although he too enjoyed some physical activities like running, his work was not quite as demanding on a physical level as participant 02's job was. Furthermore, not all his recreational and leisure activities were centred on his physical status. Nor was his place of residence connected to his physical status in the same way as participant 02's

was. Therefore, the physical changes inflicted on survivors by critical illness would not have as profound an impact on participant 18's life as they would have on participant 02's life.

Participant 02's case also provides a good example of how contextual backdrop could determine the vulnerability of survivors' lives to external influences. As his place of residence was intimately connected with his job, not being able to go back to work automatically meant that he could not return to the home he had had before his illness. This was further compounded by the fact that he had been living and working overseas at the time of his illness. Such contextual factors meant that his job as well as his place of residence was far more vulnerable to being affected by an episode of critical illness compared to a job and home that were in a person's home country.

The above examples clearly indicate that contextual backdrop can influence exactly how critical illness would affect survivors and in doing so, affect their QoL. In mapping out comprehensively the possible consequences of critical illness in the preceding chapters (Chapters 4-6), the contextual backdrop for the critical care population as a whole has already been taken into account, as participants generally talk about the changes after their illness in relation to their lives before the illness. In that sense, the contextual backdrop for the critical care population defines the boundaries of any conceptual framework (for survivors' HRQoL) that contains a comprehensive set of consequences and in doing so, is incorporated within this framework.

However, if the contextual backdrop of individuals were to be accounted for in a conceptual framework for survivors' HRQoL, survivors would have to be allowed a certain degree of freedom when it comes to defining the various areas (or domains, to use the psychologists' terminology) and sub-areas (sub-domains) that make up the conceptual framework for their HRQoL. For instance, instead of defining the sub-area 'posture and mobility' with precise items such as 'running', 'climbing stairs' and 'driving', individual survivors would have to be allowed to define the sub-area themselves, as seen in the SF-36 with the questions on role functioning and social activities. Alternatively, if the areas and sub-areas were to be precisely defined by items, survivors' perceptions of the changes mentioned in the individual items would have to be evaluated for their contextual backdrop to be taken into account (capturing perceptions is discussed later in Section 7.3 when personal factors are examined in detail).

7.2.2. Context surrounding the consequences of critical illness

The context within which the effects of critical illness are (or have been) occurring comprise of contextual factors that the International Classification of Functioning, Disability and Health classifies as environmental factors; they refer to 'the physical, social and attitudinal environment in which people live and conduct their lives' (111, p.10) and constitute the environment that survivors are discharged into after their illness. The same nomenclature for these contextual factors-environmental factors-is adopted in this document.

When talking about their lives after critical illness, study participants mentioned many of these environmental factors. Examples include:

1. Information and advice.
2. Medication.
3. Tools and aids.
4. Structural facilities (including any adaptations), especially in their homes.
5. Finances and financial support.
6. Social network (people and organizations) around them such as
 - a. Families.
 - b. Friends.
 - c. Healthcare professionals and services, including doctors, dentists, nurses, allied health care professionals and all associated services such as hospital transport, etc.
 - d. Rest of the wider society.

Such factors modulated the impact of critical illness on survivors and their lives by their presence/absence and in their behaviour. In so doing, these factors could affect survivors' HRQoL.

Before examining the modulating role of environmental factors any further, it should be highlighted that the critical illness and recovery experience itself can cause changes in these environmental factors. One example is the presence of the critical care follow-up nurse in the lives of survivors, as a result of the illness and its significant consequences.

Another example is the behaviour of survivors' family members. A number of participants spoke about how their families treated them differently after their illness. As participant 10 said, "He's got very protective, I don't know. He's terrible. He was bad enough before but he's got-- it gets a bit annoying at times. Protective, you know, and he can be over-protective.". Participant 07 was in similar position. She had been

the one who looked after everyone, but after her illness, her family was keen to look after her. She said the following, "They mollycoddle. "You can't do that, Mum", "No, you're not allowed to do that", "Don't...", I mean, they wouldn't even let me...they used to bring me my meals on a tray, they wouldn't let me carry the tray back into the kitchen, let alone stand and wash a dish, for ages and, and I got so angry, I said, "I'm only standing here, I can wash a dish, I can...", you know. Rather than encouraging me to do things they were saying, "No, you can't do that, you mustn't do that"...I know they were trying to be helpful but I just thought, well, just let me do this little... or if they did let me do something they were behind me, they were walking behind me and it was just so strange, I mean I'm not used to being looked after."

In other words, environmental factors and the critical illness and recovery experience often have reciprocal effects on each other. This reciprocity has implications. Some of the modulating effects of environmental factors would not have occurred if not for the critical illness. For instance, some study participants had significant limitations in their activities and behaviours not only because of their physical status after their illness, but also because their family imposed restrictions upon them. However, the restrictions coming from their family would not have been present if not for the fact that family had been traumatised by the critical illness experience.

Bearing this in mind, environmental factors can modulate the impact of critical illness in two different ways. First, alongside the illness, they can directly affect survivors' personal status. For instance, participant 01's arm was injured in the road traffic accident responsible for her critical care admission. As part of her medical management, a surgeon (who was essentially part of her external environment) operated on her arm and improved her physical status. Consequently, at the time of her interview, she was thinking about whether to attempt to get into the car so that she could be driven around, which she could not have contemplated before the operation.

To give another example, participant 11 suffered from marked emotional/psychological disturbances because of her multiple critical care admissions. She was experiencing frequent dreams and nightmares, had many "unrealistic fears" and was extremely anxious all the time. To help her, her follow-up nurse had been trying to lessen this emotional/psychological upheaval resulting from the critical illness(es), so that she could do more and live a more fulfilling life. As participant 11 said, "She's trying to bring the anxiety down, so that I'm not frightened to go to sleep. And what we're trying to do is break the dream down to what it really could mean.

And that it wasn't reality, it was a dream. It's not reality. That's what we're working round...she has allowed me, if you like, or enabled me to actually go out with someone. Whereas before, I didn't go out at all...so I've gained a lot of strength. A bit of confidence, but she keeps me on the right track."

Second, these environmental factors can directly temper the effects of survivors' personal status. Survivors in a given personal status may end up leading relatively different lives depending on the presence/absence and behaviour of these factors.

On the one hand, environmental factors can reduce the burden imposed on survivors by their illness. For instance, in participant 12's case, information and advice from the critical care follow-up nurse helped her do more, even though her personal status had not changed. The following extract from participant 12's interview data demonstrated this well: "I can't walk far without this [prolapsed stoma] comes out really big then and so I have to hold that as well as walking. At first, I was pushing the wheelchair but I said to *****, I feel really stupid pushing that wheelchair in shops and everything. Now, when we've got the baby, it's alright 'cause I've got her buggy. Now I'm fine with that, so now, I walk round pushing the buggy, even if she's not with us. I think well at least I can walk, I can walk further if I'm pushing something. And like we were saying, a walking stick and that, but I couldn't even do that because I'm still putting a lot of pressure and I've got to hold that [prolapsed stoma] as I'm walking, so I do find it easier pushing the buggy to let me walk further all the time. It's just things like that, that sitting talking to ***** and we've just both come up, you know, with things. One of the things she said was, have you seen the trolleys what the older people have? Well her mum is elderly and she said my mum walks with that, and she said, at least you're not, you look as if you're out shopping because you've got this trolley, which we got and that is fine because it's the way they're made now. They're just different and they come up to you, so you're just pushing the trolley. So I just feel more normal that, yeah, I am out shopping and, and I've got this trolley instead. It was just things like that...". She also received the relevant information and advice from the manufacturers of her stoma bag, which helped her better secure her bag.

This particular survivor then went on to describe a contrasting case of a man in a similar condition to her but suffered because he and his wife did not have access to the relevant information and advice. She said, "I felt sorry for him and his wife because like we did have the help of ***** and that, they weren't getting any help

at all. And we were saying to her, "Has he got, have you got a walk in shower?" She didn't know nothing about all that, so we told her to ring the OTs⁶² up and they came out and everything. It was all that, I just felt, "God that poor woman's been left to look after him by herself"...". While she did not talk about this in any great detail, this short extract effectively illustrates how the lack of informational support and advice in this man's case had negatively affected his and his wife's situation.

The situation described above with information and advice is shared by many of the environmental factors mentioned right at the beginning of this section. To give another example, participants 01 and 22 were both unable to physically climb stairs after their illness. However, participant 01 was able to get to the first floor of her house because of a stair lift installed for her after her illness. In contrast, participant 22 did not have access to this facility, and he had to sleep downstairs on the ground floor until he was well enough to climb the stairs himself.

On the other hand, although environmental factors can lessen the impact of critical illness on survivors' lives, they can also present their own set of problems and add to the burden experienced by survivors. For instance, participant 07, who had difficulty walking, found her wheelchair to be both a help and a source of frustration. As she said, "...I found walking very difficult, I got tired very easily and my daughter did get me a wheelchair to take me out and about because it was coming up near Christmas and I thought, "Oh, I can't do this and I can't do that." So she got me a wheelchair to take me shopping in, but I think we only used it once or twice and that got me more frustrated...I got fed up with that, I started walking. I just built it up gradually, and it also made me realise how many places are not wheelchair friendly. There's a lot of places aren't wheelchair friendly at all...I had to get out of the wheelchair and walk, you know. We went to a garden centre and I thought that was actually quite bad...they had trolleys that you could take round, and I thought, well, how are people going to get these trolleys round? Now whether it was because they were making alterations and they'd moved everything maybe in a bit, I don't know, but it was very difficult. And you came to dead ends, you know, you had to try and manoeuvre to get it back. It was quite difficult, you know.". Her wheelchair obviously made it difficult for her to get round in certain circumstances, even though it did help her move around more initially. As evident from the extract, it was enough of a problem for her to start walking.

⁶² Occupational therapists.

Participant 12 was in a similar situation, as seen in this extract, "I stopped using it at Christmas...to be honest it was Christmas shopping, in December, you know when the shops are packed and I said to J*** [participant's husband] "I'm not going in that wheelchair, I can't stand it." So I just said "Well I'll walk a bit" and I couldn't do much shopping but at least I was doing a bit...at first J*** [participant's husband] was frightened when I come out the wheelchair. He was frightened in case anyone knocked me, in the shops and that, but they didn't. It was worse being in the wheelchair. I had some woman near fall on me when I was in the wheelchair. They just don't see you at all and that's what I hated.". As in participant 07's case, participant 12's wheelchair had made things worse for her in some ways.

Another example of environmental factors adding to the effects of critical illness would be the restrictions and frustration experienced by survivors as a result of the behaviour of their family after their illness. Both participant 07 and 25 vividly described this, as seen in the following extracts from their interviews.

Participant 07:

"...when I first came out I got really frustrated because, A, I couldn't do things that I wanted to do, B, the family tried to stop me doing things I wanted to do..."

Participant 25:

"...my mum was going to stay and she was ready to stay forever, but I just-- like I'd be going to the toilet and it was such an effort to try and get up to sit on the toilet; she'd be outside going, "You alright?" "I'm going to the toilet." "Been in there a long time, darling." "No, I'm fine Mum." "I'm sure you'll hear the bang if, you know." And in the end she said, "Oh, I've got to go home and see your dad," and I just pretended that I thought she meant forever, and I said, "Oh, you know, I'll be fine on my own,"...she only stayed for-- I think it was probably a couple of weeks at the most, and then I just couldn't stand it any more. In the nicest possible way."

From the discussion, it is clear that environmental factors can positively or negatively affect survivors, against the background of changes already caused by their critical illness. When reporting the changes after critical illness, the study participants did not always distinguish between the effects of the critical illness itself and those of the environmental factors. Therefore, while it is not conventional in HRQoL measurement research to separately identify the effects of environmental factors, one

should be aware that a truly patient-based conceptual framework for survivors' HRQoL often captures not only the effects of critical illness but also (at least some of) the effects of these environmental factors.

This concludes the discussion on contextual factors. The next section focuses on personal factors.

7.3. Personal factors

Personal factors refer to the personal characteristics inherent within the critical care survivor himself/herself (105, 111). Examples of such factors from the literature and from the interview data include age, sex, current and past experiences, goals and expectations, coping mechanisms, emotional/psychological status such as values and personal preferences, personality traits and even the concurrent changes that survivors are experiencing (105, 111-113). Many of these personal factors are heavily intertwined with one another. For instance, participants' expectations were often influenced by their age and previous experiences.

These personal factors affect survivors' HRQoL by influencing their perceptions of the changes that have occurred/are occurring to them after their critical illness, such that the QoL implications for a given change may differ between survivors.

A good illustration of how such factors can affect survivors' perceptions is demonstrated by the interview data from participants 07 and 24. In these two cases, age was the personal factor that made the difference. Participant 07, who was in her 60s, made several references to the fact that she expected certain changes as she grew older, such as being more tired after walking a significant distance. She even wondered aloud whether her being more emotional after her critical illness had to do with her becoming older. She appeared to accept that certain changes were inevitable with age. She therefore seemed fairly unperturbed by the changes, which meant that these changes only had a minimal impact on her QoL even though they limited her life.

In contrast, participant 24, who was only in her 30s, made the point that she found many of her limitations difficult especially because she was young. Like she said, "...everyday things are different, like cleaning, shopping, I find them really difficult...then I get really bad pains in my back, I can't breathe...I'm on seven inhalers, tablets for breathing, heart tablets, and I get really bad pains in my chest and back. Can't go up and down the stairs in one go, just can't carry shopping, can't play with my kids the way I used to play with my kids, I mean I'm only young, I'm only 30,

so I find that really difficult...". Although she did not articulate it outright, she implied during this excerpt that because she was young, she expected to be able to do many of the things that she could no longer do. Being less accepting of the changes in her life, it was very probable that her QoL would be more adversely affected compared to someone who did not find the changes as difficult.

To give another example, participants 10 and 13 had very different priorities with regard to going back to work. For participant 10, returning to work was important for her. As she said, "I think I will feel that I've achieved something and I've come on once I get back to work...I feel a little bit abnormal because I can't work and as I say, 23 years in--, well near enough 23 years in the same job, and I have an insurance I had to fill out while I was in hospital,...by the side of "sickness record," it had "no record of sickness.""

In contrast, participant 13 did not really talk about wanting to go back to work at all. In fact, he talked about not wanting to return to the rat race, which seemed to be how he perceived work. He said the following, "The most important thing is that I'm progressing. Myself. And trying to progress and striving for a better quality of life really. And doing things that I could never have done before because I was, like, too inebriated or too busy working. And I do have ambitions. I do have goals that I yet have to achieve. But I don't want to be caught in this rat race any more. I really do not. I've been there, you know, and I've earned lots of money and I've travelled with my work and met a lot of interesting people and had some really good times and good experiences, but at the end of the day, it did not feed my soul. And I really am at a point in my life where I have to do something where I actually feel that I'm benefiting from it and somebody else is. And industry and the rat race isn't for me...I'd like to go and live in the woods really. That would be nice. A log cabin in the woods. Like Grizzly Adams. Just live in the wilderness away from people and away from society and the pressures of modern-day society. In an ideal world, that's what I would do. Just be me and my kids and be living in the hills like Hilly Billies. Living off the land. You know? Solar power and a wind generator. Ecologically sound home. And self-sustaining. Self-supporting."

With such different priorities, not being able to return to work because of their personal status would be perceived very differently by participant 10 and 13, and therefore, the fact that they were not in a state to go back to work at the time of the interview would have very different QoL implications for them.

From these data, it is clear that survivors' personal characteristics have considerable influence over survivors' HRQoL through their effects on survivors' perceptions of any change that occurs after critical illness. Correspondingly, different survivors often perceive each domain (or sub-domain of a conceptual framework for survivors' HRQoL) differently and thus, the actual contribution a particular domain (or sub-domain) makes towards a survivor's HRQoL tends to vary across survivors.

Before concluding this section on personal factors, it is important to point out that like environmental factors, these factors can be affected by the critical illness and recovery experience. For instance, before their illness, both participant 07 and 10 had highly valued getting their domestic chores and activities done as quickly as possible. However, their priorities changed after their illness and they preferred to spend more time with their loved ones instead. This means that not being able to carry out domestic chores and activities was likely to matter less to these participants after their illness when compared to before their illness.

In addition, personal factors may also change over time as survivors respond and adapt. For example, participant 13, after a period of time, began to accept what has happened to him, and this affected the way he perceived his life. He realised that his life could still be fulfilling whereas previously, he felt that he was just 'living an existence'. As he said during his interview, "I've accepted now that I'll never be one hundred percent again but I can do my best, you know and have a fulfilling life...I've got out of this doom and gloom cycle, you know, because that's how I felt and more acceptance really, you know, accepting well I do have to take lots of medication and I do get lots of problems with my legs."

Therefore, personal factors can change as survivors move through their critical illness and recovery experience. This means that a given change can have different implications for a particular survivor's QoL at different points in time, which in turn means that the influence exerted by a particular domain (and sub-domain within a conceptual framework for survivors' HRQoL) over a survivor's HRQoL may vary over time.

7.4. Conclusion

Contextual and personal factors have a crucial role to play in survivors' concept of HRQoL. Contextual factors (contextual backdrop and environmental factors) help define and modulate the exact consequences of critical illness. In so doing, contextual factors (specifically, contextual backdrop) help delineate the boundaries of the domains (and sub-domains) of a conceptual framework for

survivors' HRQoL. In addition, the effects of contextual factors (specifically, environmental factors) are often captured by a conceptual framework for survivors' HRQoL, especially when the framework is heavily patient-based. This is because the effects of these contextual factors are frequently so intermingled with the consequences of critical illness that they are virtually inseparable from one another.

With respect to personal factors, they affect survivors' perceptions of the changes that have occurred/are occurring after their critical illness. Thus, these factors define the contribution each domain (and sub-domain of the framework) makes towards a survivor's HRQoL.

Having highlighted the role of contextual and personal factors in survivors' HRQoL and reviewed how these factors would interact with and/or be captured by an eventual conceptual framework for survivors' HRQoL, the next chapter focuses on: (i) finalising a patient-based framework for survivors' HRQoL using the findings of the study; and (ii) utilising the framework to assess the extent to which the current expert consensus generic measures-the SF-36 and EQ-5D-capture survivors' HRQoL. Such an evaluation is important, as it clarifies the domains (and sub-domains) that would definitely need to be included in a specific measure for critical care survivors.

Chapter 8: Content mapping between expert consensus generic measures and patient-based conceptual framework for survivors' HRQoL

8.1. Introduction

In Chapters 4-7, all the aspects of survivors' lives that have implications for their HRQoL have been described. In this chapter, the extent to which the current expert consensus generic measures for survivors-the SF-36 and EQ-5D-capture these various aspects of survivors' HRQoL is evaluated. Such an evaluation helps with recommendations concerning the domains and sub-domains to include in a specific measure, so that the concepts in the specific measure are complementary to those covered by the expert consensus generic measures. Having minimal overlap between the concepts measured by generic and specific measures used in survivors is desirable, given that survivors tend to be frail and respondent burden is a major consideration.

To enable this assessment, the information from these preceding chapters, Chapters 4-7, is distilled and used to refine the preliminary conceptual framework for HRQoL of survivors, to yield a final, patient-based conceptual framework for the HRQoL of survivors. This framework, alongside the detailed findings of its various elements, is then used to assess the extent to which the SF-36 and EQ-5D are sufficient in capturing survivors' HRQoL.

The chapter first describes the methods used to achieve the two main goals of the work outlined above, namely:

- To finalise the patient-based conceptual framework for HRQoL of survivors.
- To evaluate the extent to which expert consensus generic measures are capturing survivors' HRQoL.

The final, patient-based framework is then presented, before the extent to which the SF-36 and EQ-5D are sufficient in capturing survivors' HRQoL is reported.

8.2. Methods

8.2.1. Construction of final, patient-based conceptual framework

After using qualitative interviews to seek survivors' views of what constitutes HRQoL for them, the data obtained were organised into emergent categories and key themes. These categories and themes were then used to revise the preliminary conceptual framework for survivors' HRQoL to yield a final, patient-based conceptual framework for survivors' HRQoL.

8.2.2. Evaluation of the extent to which the current expert consensus generic HRQoL measures capture the patient-based conceptual framework

To assess the extent to which the SF-36 and EQ-5D capture the various aspects of survivors' HRQoL, as detailed in the final, patient-based conceptual framework, two methods were employed:

- The content of both questionnaires was examined alongside data collected from the qualitative interviews of survivors, to determine how well these questionnaires captured the different domains and sub-domains outlined in the patient-based conceptual framework (essentially a representation of survivors' HRQoL).
- The study participants were invited to complete either the SF-36 or the EQ-5D as part of their 'questerview' (1). Participants 01, 03, 05, 07, 10, 12, 14, 16, 18, 20, 22 and 24 completed the SF-36 while participants 02, 04, 06, 08, 09, 11, 13, 15, 17, 19, 21, 23 and 25 answered the EQ-5D. Next, participants were asked for their opinion on how accurately the questionnaire they completed reflected their thoughts about their health and QoL, and also to identify important areas not addressed in the questionnaire.

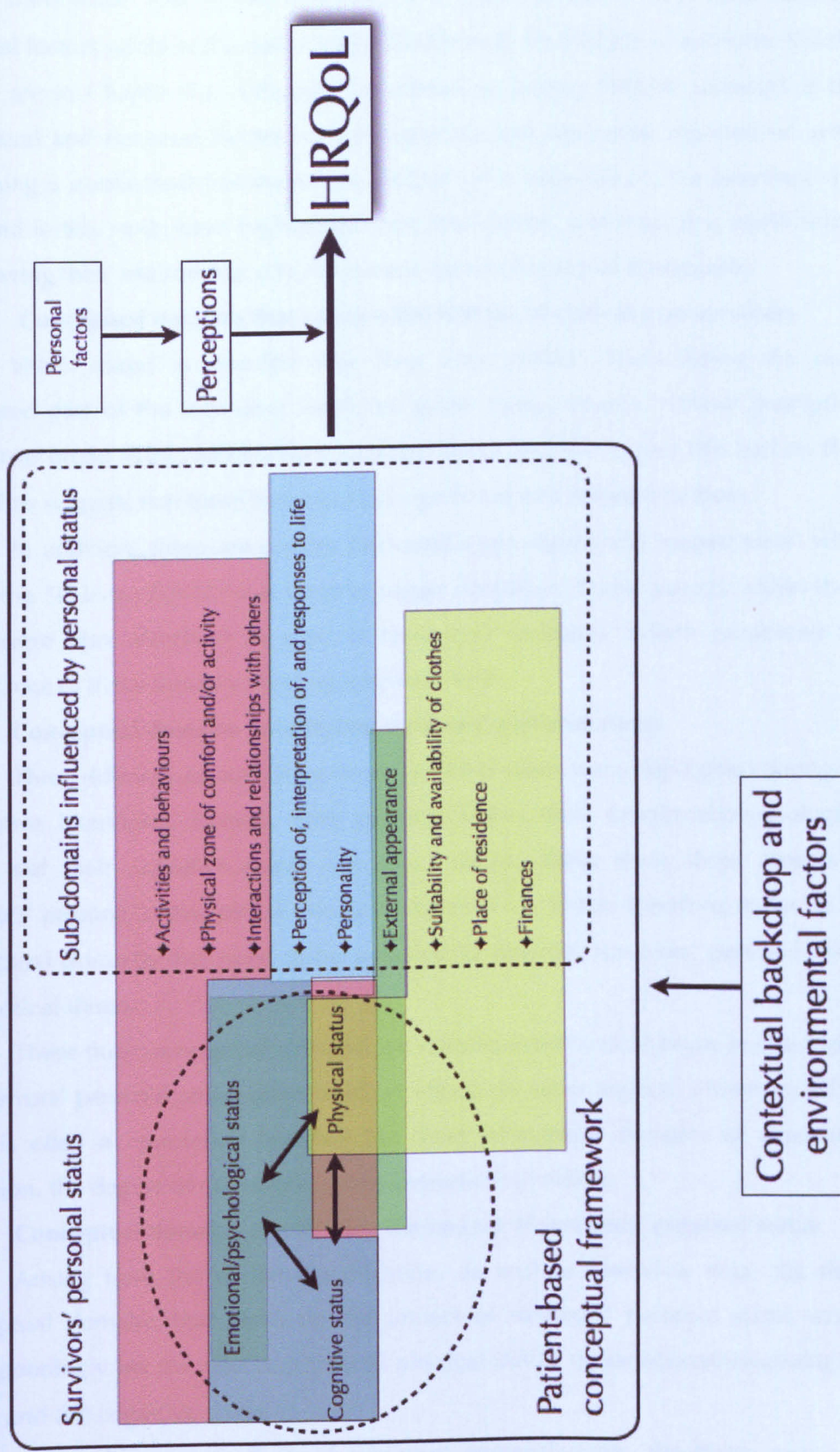
8.3. Patient-based conceptual framework

The patient-based conceptual framework comprises two parts:

- Survivors' personal status.
- Impact of survivors' personal status.

Figure 8.1 shows the patient-based conceptual framework, together with its relationships with contextual (contextual backdrop and environmental factors) and personal factors. This patient-based framework draws chiefly on the data obtained during the semi-structured part of the interviews, with some additional information gleaned from the 'questerview' component. In order to fully reflect survivors' perspective, the framework has been structured in much the same way as how study participants have viewed and spoken about the impact of critical illness.

Figure 8.1: Patient-based conceptual framework and its relationships with contextual and personal factors



This section first discusses the conceptual domains that capture the two parts of this framework. This is then followed by a quick review of how contextual and personal factors relate to the patient-based framework for HRQoL of survivors (Further details are in Chapter 7.). Although the orthodoxy among HRQoL scientists is that contextual and personal factors are not explicitly and separately reported on when discussing a conceptual framework for HRQoL (of a population), the interview data obtained in this study have highlighted their importance, and thus, it is worth briefly considering their relationship(s) to the patient-based conceptual framework.

8.3.1. Conceptual domains that capture the HRQoL of critical care survivors

When asked to describe their lives after critical illness during the semi-structured part of the interview, survivors spoke freely, usually without prompting, about two broad areas, namely their personal status and the impact this had on their lives. This suggests that these two areas are significant and relevant to them.

In addition, these areas were discussed again during the 'questerview' when either the SF-36 or EQ-5D was used to trigger narratives. Some aspects within these areas were also identified as gaps in these two measures, which reinforced the importance of these areas in affecting survivors' QoL.

A. Conceptual domains constituting survivors' personal status

Three different aspects of survivors' personal status were highlighted during the qualitative interviews, namely, their physical status, their emotional/psychological status and their cognitive status (For exact details about these three aspects of survivors' personal status, please refer to Chapters 4-6.). These, therefore, make up the conceptual domains that need to be included to describe survivors' personal status after critical illness.

These three conceptual domains are interdependent, as changes in one aspect of survivors' personal status often result in effects on other aspects. However, whilst there is often a correlation between the three conceptual domains of a person's condition, the degree of correlation varies between individuals.

B. Conceptual domains constituting the impact of survivors' personal status

Arising from the earlier classification, as well as interview data, the three conceptual domains that make up the impact of survivors' personal status would correspondingly be: the effects of their (i) physical status, (ii) emotional/psychological status, and (iii) cognitive status.

As for the precise effects of survivors' personal status, the three aspects of survivors' personal status can have mutual influence over one another. In addition,

there are also other wide-ranging consequences that can be divided into the following areas:

- Perception of, interpretation of, and responses to life.
 - Effects due to emotional/psychological status.
 - Effects due to cognitive status.
- Personality.
 - Effects due to emotional/psychological status.
 - Effects due to cognitive status.
- External appearance.
 - Effects due to physical status.
 - Effects due to emotional/psychological status.
- Activities and behaviours.
 - Effects due to physical status.
 - Effects due to emotional/psychological status.
 - Effects due to cognitive status.

These affect:

- Posture and mobility:
 - Personal posture and mobility (i.e. posture and mobility involving a person's body).
 - Using transport.
 - Driving (includes driving a car, riding a bike, etc).
- Sleep/rest.
- Communication.
- Self-care activities.
- Activities associated with societal roles such as domestic chores, learning activities and paid work.
- Other activities:
 - Recreational and leisure activities; both sedentary pursuits, like reading, and physically active pursuits, e.g. going to the gym and dancing classes.
 - Social activities.
 - Sexual activity (including physical contact with a partner/spouse).
- Physical zone of comfort and/or activity.
 - Effects of physical status.

- Effects of emotional/psychological status.
- Effects of cognitive status.
- Suitability and availability of clothes.
 - Effects of physical status.
- Interactions and relationships with others.
 - Effects of physical status.
 - Effects of emotional/psychological status.
 - Effects of cognitive status.
- Place of residence.
 - Effects of physical status.
- Finances.
 - Effects of physical status.

The effects of survivors' personal status in these different areas constitute the various sub-domains of the three main conceptual domains.

When delineating the impact of survivors' personal status with respect to their QoL, the goal has been to be as comprehensive as possible. Therefore, every effect described influenced the QoL of at least *some*, but not necessarily all, survivors. Furthermore, even amongst those whose QoL was affected, the degree to which their QoL was influenced varied. This is because each survivor would have perceived a given effect differently (This has already been discussed in Chapter 7, Section 7.3. Please refer to that section for more details.).

8.3.2. Relationship of contextual and personal factors to patient-based conceptual framework (Details in Chapter 7)

The interview data indicate that relationships exist between the patient-based conceptual framework for survivors' HRQoL and contextual (that is, contextual backdrop and environmental factors) and personal factors. The contextual backdrop of survivors influences the exact consequences of critical illness and therefore, it helps define the boundaries of the domains (and sub-domains) of the patient-based conceptual framework for survivors' HRQoL. With regard to environmental factors, many of their effects are frequently captured by the patient-based conceptual framework for survivors' HRQoL. This is because the framework represents the consequences of critical illness reported as significant by survivors interviewed and these survivors, when describing the consequences, were often speaking about the resultant impact of both the critical illness and environmental factors, rather than consequences stemming from the critical illness alone. As for personal factors, given

that they affect survivors' perceptions of the changes in their lives after critical illness, they determine the contribution made by each domain and sub-domain of the conceptual framework to survivors' HRQoL.

8.4. How well does the current expert consensus generic measures capture survivors' HRQoL?

In this section, the extent to which the current expert consensus generic measures capture survivors' HRQoL is evaluated and discussed. The results of this evaluation are summarised in Table 8.1.

Table 8.1: Content mapping between the expert consensus generic measures and the patient-based framework

Domains and sub-domains of patient-based framework	SF-36	EQ-5D
Physical status, including physical consequences from emotional/psychological status and cognitive status.	●	●
Emotional/psychological status, including emotional/psychological consequences from physical status and cognitive status.	○	○
Cognitive status, including cognitive consequences from physical status and emotional/psychological status.	○	○
Perception of, interpretation of, and responses to life: <ul style="list-style-type: none">• Impact of emotional/psychological status.• Impact of cognitive status.	○ ○	○ ○
Personality. <ul style="list-style-type: none">• Impact of emotional/psychological status.• Impact of cognitive status.	○ ○	○ ○
External appearance. <ul style="list-style-type: none">• Impact of physical status.• Impact of emotional/psychological status.	○ ○	○ ○

Domains and sub-domains of patient-based framework		SF-36	EQ-5D
Activities and behaviours.			
• Impact of physical status.		●	●
• Impact of emotional/psychological status.		●	●
• Impact of cognitive status.		●	●
Physical zone of comfort and/or activity.			
• Impact of physical status.		○	○
• Impact of emotional/psychological status.		○	○
• Impact of cognitive status.		○	○
Suitability and availability of clothes.			
• Impact of physical status.		○	○
Interactions and relationships with others.			
• Impact of physical status.		○	○
• Impact of emotional/psychological status.		○	○
• Impact of cognitive status.		○	○
Place of residence.			
• Impact of physical status.		○	○
Finances.			
• Impact of physical status.		○	○

● : Generally captured by questionnaire; ● : Inconsistently and/or incompletely captured by questionnaire; ○ : Not captured by questionnaire.

8.4.1. Content mapping between the SF-36 and the patient-based conceptual framework

The SF-36 is a health survey comprising thirty-six questions which measures eight health concepts: physical functioning (PF); role limitations because of physical health problems (RP); bodily pain (BP); general mental health (psychological distress and psychological well-being) (MH); role limitations because of emotional problems (RE); social functioning (SF); vitality (energy/fatigue)(VT) and general health perceptions (GH) (114) (These questions are reproduced in Table 8.2 for ease of reference.).

Table 8.2: Questions in the SF-36

1. In general, would you say your health is:

2. Compared to one year ago, how would you rate your health in general now?

3. The following questions are about activities you might do during a typical day.
Does your health now limit you in these activities? If so, how much?

a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.

b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.

c. Lifting or carrying groceries.

d. Climbing several flights of stairs.

e. Climbing one flight of stairs.

f. Bending, kneeling or stooping.

g. Walking more than a mile.

h. Walking several hundred yards.

i. Walking one hundred yards.

j. Bathing or dressing yourself.

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

a. Cut down on the amount of time you spent on work or other activities.

b. Accomplished less than you would like.

c. Were limited in the kind of work or other activities.

d. Had difficulty performing the work or other activities (for example, it took extra effort).

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?
 - a. Cut down on the amount of time you spent on your work.
 - b. Accomplished less than you would like.
 - c. Did work or other activities less carefully than normal.
6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?
7. How much bodily pain have you had during the past 4 weeks?
8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...
 - a. Did you feel full of life?
 - b. Have you been very nervous?
 - c. Have you felt so down in the dumps that nothing could cheer you up?
 - d. Have you feel calm and peaceful?
 - e. Did you have a lot of energy?
 - f. Have you felt downhearted and low?
 - g. Did you feel worn out?
 - h. Have you been happy?
 - i. Did you feel tired?
10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc)?
11. How true or false is each of the following statements for you?
 - a. I seem to get ill more easily than other people.
 - b. I am as healthy as anybody I know.
 - c. I expect my health to get worse.
 - d. My health is excellent.

In the rest of this subsection, I evaluate the extent to which the SF-36 captures the important conceptual domains and sub-domains of survivors' HRQoL.

A. Capture of survivors' personal status

Three main conceptual domains need to be assessed where survivors' personal status is concerned: physical status, emotional/psychological status and cognitive status.

The SF-36 contains direct questions aimed at physical status and emotional/psychological status. It does not have any explicit questions directed specifically at cognitive status but empirical evidence, as well as study data, indicate that it is not completely insensitive to cognitive changes (114).

I. Domains which are captured

All three relevant conceptual domains may be captured by the questions on general health perceptions, Questions 1 and 11, but this does not happen consistently across survivors. Questions 1 and 11 do not define the term 'health'. Instead, they allow the survivors answering the questions a certain degree of freedom of interpretation. Therefore, the extent to which these questions capture each of the three conceptual domains is entirely dependent on how survivors answering the questions define the term 'health'.

At one end of the spectrum, there are survivors like participant 23, whose definition of health was very broad, and included physical status, emotional/psychological status and cognitive status. For these survivors, Questions 1 and 11 would cover all three conceptual domains. At the other end of the spectrum, there are survivors like participants 07 and 20, who had a much narrower view of the term 'health' and saw it as referring simply to physical status. In such cases, these questions would end up capturing only the domain 'physical status'.

The domain of physical status appears to be universally captured, at least to some extent, by Questions 1 and 11. All study participants seemed to consider physical status part of health, but one case demonstrated that there were occasions where not every physical change was captured by the term 'health'. Participant 12 ended up with a prolapsed colostomy after her illness but due to the fact that she did not feel ill with it, she did not incorporate this change into her assessment of health. As such, this particular physical change was not captured by Questions 1 and 11.

In comparison, the domains of 'emotional/psychological status' and 'cognitive status' are much less consistently captured by these questions. While physical status is almost synonymous with health, the incorporation of emotional/psychological status

and cognitive status into the definition of health seems less universal. For example, participant 20 said that the SF-36 should not include questions on emotional problems and made the point that if he was to design a questionnaire on health, he would not be asking about emotional/psychological status. For him, health was solely about physical status.

Besides Questions 1 and 11 on general health perceptions, the SF-36 also has other questions directly assessing aspects of physical status and emotional/psychological status.

Where physical status is concerned, Questions 7 and 9 (parts a., e., g., and i.) enquire about pain and fatigue, respectively. Both these questions are relevant as they assess aspects of physical status that are of importance to (at least some) survivors. In particular, Question 9 on fatigue captures a specific aspect of physical status that is especially relevant for survivors. Besides it being almost universal among participants, it could be very pronounced and long lasting. In fact, certain survivors, such as participant 08, explicitly asserted that it should be assessed.

Nonetheless, there are two important issues to raise in terms of this assessment of specific aspects of physical status by the SF-36. First, the SF-36 specifically assesses pain (Question 7). However, pain does not appear to be a more common or bigger problem for survivors compared to other physical changes, even though it is generally considered an important concept to assess when it comes to HRQoL (114-116) and remains very relevant for some survivors (such as participants 05 and 10). Physical changes such as marked weakness are more frequent complaints among survivors, while for survivors such as participants 12 and 23, the physical complaints that were more troubling for them were a prolapsed stoma and incontinence, respectively. Therefore, although pain is specifically evaluated, it is important to remember that survivors experience a multitude of other physical changes, many of which may be more significant (to them individually and as a group) than pain.

Second, Question 9 does not distinguish between physical fatigue (a physical problem) and mental fatigue (which is, strictly speaking, an emotional/psychological problem), a distinction that survivors such as participant 25 made. This means that although it captures physical fatigue (the physical problem), it will also capture mental fatigue, an emotional/psychological problem, at the same time if that were present. If it were deemed desirable to have specific information on physical fatigue, additional questions would need to be asked.

Moving on to emotional/psychological status, the question (other than Questions 1 and 11) that will capture this domain is Question 9 (all parts). Question 9 will cover the specific aspects of anxiety, depression and fatigue (specifically mental fatigue if it is present). These are all fairly prominent emotional/psychological changes for many survivors and thus, the questions are very relevant.

Nonetheless, anxiety, depression and mental fatigue are not the only emotional/psychological changes that are reported by survivors and/or are important to survivors. Many of the changes not assessed appeared to be as pronounced (if not even more so) and/or more specific to this population than anxiety, depression and mental fatigue were for participants. For instance, a multitude of emotional/psychological changes from negative ones such as nightmares, flashbacks and feelings of frustration and anger to positive emotional/psychological ones such as feelings of being lucky enough to be given a second chance in life were reported by study participants. In fact, during their 'questerview', survivors such as participants 07 and 22 pointed out that emotional/psychological changes such as nightmares and intrusive memories were not assessed but should be. This supports the fact that for survivors, some of these other emotional/psychological changes are just as important (if not more important) to capture as anxiety, depression and mental fatigue when it comes to the conceptual domain of emotional/psychological status.

Moreover, as already stated, the question on fatigue, Question 9 (parts a., e., g., and i.), does not differentiate between mental and physical fatigue and simply assesses fatigue as a whole. Therefore, an assessment of the emotional/psychological change of mental fatigue using the SF-36 will always be contaminated with information about physical fatigue. Similar to the situation with physical fatigue, if it were viewed that specific information on mental fatigue is important, additional questions on mental fatigue would be required.

In summary, the SF-36 consistently captures for survivors:

- An overview of physical status, as well as the specific aspects of pain and physical fatigue.
- Three specific aspects of emotional/psychological status, namely, mental fatigue, anxiety, and depression.

In addition, depending on survivors' definition of 'health', the SF-36 may sometimes also capture:

- An overview of emotional/psychological status.
- An overview of cognitive status.

II. Gaps in the coverage of critical care survivors' personal status

When it comes to survivors' personal status, the gaps lie mainly in the inadequate capture of survivors' emotional/psychological status and cognitive status.

Regarding the assessment of survivors' emotional/psychological status, there are two main shortfalls. First, as already mentioned, the SF-36 only assesses fatigue as a whole, with no separation of the concepts of mental fatigue and physical fatigue. Consequently, an assessment of survivors' emotional/psychological status will inevitably also capture information on survivors' physical status. Thus, if precise information were required on survivors' emotional/psychological status, or more specifically, on mental fatigue, additional questions would be warranted.

Second, the SF-36 may not always capture survivors' emotional/psychological status completely. As already discussed above, Questions 1 and 11 do not consistently capture a general overview of survivors' emotional/psychological status. In addition, although the SF-36 consistently captures three emotional/psychological changes important to survivors (anxiety, depression; and mental fatigue), it does not directly and specifically ask about several other significant emotional/psychological changes that study participants have reported. With no direct questions on these emotional/psychological changes, coupled with Questions 1 and 11 inconsistently capturing an overview of survivors' emotional/psychological status, emotional/psychological changes important to survivors are not always captured. This renders SF-36's coverage of the conceptual domain of survivors' emotional/psychological status incomplete.

With respect to cognitive status, the SF-36 does not directly capture this conceptual domain in a consistent fashion. In some survivors, it may not capture this conceptual domain at all. As already mentioned, Questions 1 and 11 will capture an overview of survivors' cognitive status only when their definition of the term 'health' includes cognitive status. Not all survivors include cognitive status in the definition of the term 'health', and thus, Questions 1 and 11 may not always capture cognitive status. In addition, in contrast to the situation with physical status and emotional/psychological status, the SF-36 does not have any specific questions directly aimed at capturing this particular domain. There are no questions on areas of cognitive status frequently spoken about by survivors, such as memory, concentration, language, and the ability to carry out complex mental tasks such as forming judgments and opinions or making decisions and problem solving. The fact that the SF-36 does not directly evaluate cognitive status is supported by the fact that some participants

themselves recognized and mentioned this gap (with and without prompting) during the 'questerview'. Participant 05 pointed out, without reminder or encouragement of any sort, that concentration (part of cognitive status) was not covered in the SF-36 while participants 07, 12 and 22 agreed, with some prompting⁶³ from the interviewer, that cognitive changes were not captured in the SF-36. In addition, participant 07 volunteered that memory problems were not included in the SF-36 when the prompt in her case referred only to concentration.

Although the SF-36 does not directly evaluate survivors' cognitive status, one can argue that the questionnaire still captures (some) cognitive changes, because there is evidence to suggest that these changes may be captured by the SF-36 indirectly. The study data indicate that survivors' cognitive status is linked to aspects of their physical and emotional/psychological statuses directly assessed by the SF-36. For instance, participant 13 spoke vividly about how his poor memory had caused him a lot of anxiety (assessed by Question 9 of the SF-36). Although his anxiety was not entirely due to his cognitive changes, there was no doubt that there were occasions when they aroused his anxiety. As another example, participant 17's cognitive changes were the result of depression (again, assessed by Question 9 of the SF-36). When her depression was treated, her cognitive changes also resolved to a considerable extent. With such survivors, their cognitive status was somewhat linked to their emotional/psychological status. This kind of connection is not limited to that between cognitive status and emotional/psychological status, a similar link was also seen between cognitive status and physical status. For example, participant 13's lack of concentration and poor memory led to marked fatigue (also assessed by Question 9 of the SF-36) because it resulted in him doing multiple jobs at any one time. With such links, it may be argued that the answers to the questions on these aspects of physical status and emotional/psychological status in the SF-36 can provide insights into survivors' cognitive status, even though there are no questions directly capturing cognitive status in the SF-36.

On the other hand, not every participant who suffered cognitive decline reported clear correlations between their cognitive status and other aspects of their

⁶³ Quite a number of study participants spoke about their cognitive problems during the semi-structured part of the interview. When that was the case, some of them were directly asked whether the SF-36 captured cognitive status and whether it was important for them that it did. The others were not prompted in the same way, first, because there was the concern that survivors might agree with the prompt(s) regardless of what they truly thought, and second, they had raised other issues that needed to be explored in more detail and it was not feasible to carry on prompting (example, respondent fatigue, etc).

personal status. Moreover, even for survivors in whom there was a definite connection, the degree of correlation differed across survivors. With the available data, there is no way of predicting, with any certainty, the degree of correlation that exists (if any does exist) in a particular survivor. If the physical and emotional statuses of survivors were to be used as markers for their cognitive status, more research would have to be done, first, to determine the accuracy of using such a method and second, to establish how to use the method in such a way that the results obtained would be a good estimation of cognitive status in individual survivors. Therefore, though the SF-36 assesses domains linked to survivors' cognitive status, it cannot be used to yield an accurate estimate of cognitive status.

With inconsistent capture of cognitive status by Questions 1 and 11, the lack of direct questions and the inability to obtain an accurate estimation of cognitive status via the domains assessed by the SF-36, the conceptual domain of cognitive status is not well captured by the SF-36.

In summary, the three conceptual domains of survivors' personal status are captured to varying degrees by the SF-36. Physical status is most consistently captured while cognitive status is the least well covered. Capture of emotional/psychological status falls in between that of physical status and cognitive status.

B. Coverage of the impact of survivors' personal status

The three conceptual domains that constitute the impact of survivors' personal status are: effects of physical status; effects of emotional/psychological status; and effects of cognitive status.

The situation with regard to capturing the impact of survivors' personal status is similar to that seen in the assessment of survivors' personal status. The SF-36 has questions directed at assessing the effects of physical status and emotional status but it does not contain any specific questions directed at capturing the effects of cognitive status. Nonetheless, subject to certain conditions, the SF-36 may still capture some of the effects of cognitive status.

I. Effects captured by the SF-36

As discussed in Section 8.4.1A, Subsection I, Questions 1, 7, 9 and 11 capture the three conceptual domains of survivors' personal status (to varying degrees). In doing so, they will capture some of the mutual effects physical status, emotional/psychological status and cognitive status exert on one another. Consistent with what has already been discussed, physical consequences will be captured most completely, cognitive consequences least completely, with capture of

emotional/psychological consequences lying somewhere in between the two. In any case, because Questions 7 and 9 specifically assess pain, fatigue (mental and physical), anxiety and depression, the consequences of pain, fatigue (mental and physical), anxiety and depression will always be captured, should they occur.

As for the rest of the effects of survivors' personal status, the effects that the SF-36 consistently captures are:

- Some of the effects of physical status on activities and behaviours.
- Some of the effects of emotional/psychological status on activities and behaviours.

Questions 3, 4, 6, 8 and 10 capture the impact of physical status on the following (groups of) activities and behaviours:

- Personal posture and mobility.
- Self-care activities.
- Activities associated with societal roles.
- Social activities.

However, it must be said that the questions on social activities do not distinguish between the effects of physical status and those of emotional/psychological status. Consequently, specific information on the impact of physical status on social activities will not be available. If such data were deemed important, additional questions would be needed.

Besides capturing the impact of physical status on the abovementioned (groups of) activities and behaviours, the data indicate that the questions may also capture the effects of physical status on driving and recreational and leisure activities under certain conditions.

In terms of capturing the impact of physical status on driving, driving had been part of work for survivors such as participants 01 and 05, and thus, their ability to drive consequent to their physical status would be picked up by Question 4 of the SF-36 (this question assesses activities associated with societal roles, which includes work).

As for capturing the effects of physical status on recreational and leisure activities, some participants took the examples used to demonstrate the terms 'vigorous activities' and 'moderate activities', in Question 3, very literally. Under such circumstances, the impact of physical status on certain recreational and leisure activities would be captured, although Question 3 is primarily aimed at capturing only the effects on personal posture and mobility, and self-care activities. (Strictly speaking,

activities associated with societal roles, specifically, domestic chores, would also be captured when survivors chose to interpret the question in that way. However, in this case, the capture of these activities does not further extend SF-36's coverage of the impact of physical status on activities and behaviours.).

In addition, survivors like participant 10 interpreted Questions 4 and 8 as including recreational and leisure activities when these questions were only asking about activities associated with societal roles. Activities associated with societal roles specifically refer to any of the following: child-care, community activities, volunteer work, work activities, housework and schoolwork (31). These activities do not include recreational and leisure activities, but evidence from the study indicate that Questions 4 and 8 may still capture them.

Finally, some social activities are also recreational and leisure activities. When that is the case, recreational and leisure activities would be captured by Questions 6 and 10.

Nevertheless, while there are instances within the study data when the SF-36 does capture the impact of physical status on driving and recreational and leisure activities, such instances have occurred only because certain conditions have been fulfilled. Some survivors interpreted questions in their own idiosyncratic way (totally in keeping with their individual circumstances and within reason). At other times, it was because these (groups of) activities also fell under (groups of) activities assessed by the SF-36. Such situations did not happen consistently across survivors. Therefore, the ability of the SF-36 to capture the effects of physical status on driving and recreational and leisure activities should be treated as the exception rather than the rule. In general, it should be assumed that the impact of physical status on driving and recreational and leisure activities are not captured by the SF-36.

When it comes to the impact of emotional/psychological status on activities and behaviours, Questions 5,6 and 10 capture the effects of emotional/psychological status on:

- Activities associated with societal roles
- Social activities.

Nonetheless, as already stated, the questions on social activities (Questions 6 and 10) do not separate the impact of emotional/psychological status from that of physical status on such activities. Hence, should precise information be required on the effects of emotional/psychological status on social activities, additional questions would have to be asked.

It should also be mentioned that Questions 5, 6 and 10 may also capture the effects of emotional/psychological status on driving and recreational and leisure activities. This is because, as already explained earlier, activities associated with societal roles and social activities may cover driving and recreational and leisure activities under certain circumstances. However, as also discussed, this did not happen consistently across survivors, and hence, the SF-36 capturing the impact of emotional/psychological status on driving and recreational and leisure activities should not be considered the norm.

Besides Questions 5, 6 and 10, Question 3 may also cover the impact of emotional/psychological status on activities and behaviours. It may capture the effects of emotional/psychological status on personal posture and mobility, and self-care activities under specific conditions. This question simply asks whether health in general affects personal posture and mobility, and self-care activities. Therefore, hypothetically speaking, if a person is unconfident about climbing stairs, views it as a limitation and answers Question 3, as such, the restriction imposed by a person's emotional/psychological status on this particular activity would have been captured by this question.

While this particular way of thinking and answering the question was not specifically explored with study participants in relation to Question 3, there was some evidence from participant 03's interview data to suggest that it could happen. When answering Question 4, participant 03 highlighted the fact that she accomplished less than she would have liked (essentially, a limitation) because of her lack of confidence in certain activities such as climbing stepladders and gripping her crystal ware. Therefore, although the notion of Question 3 capturing some of the effects of emotional/psychological status in personal posture and mobility is more of a theoretical notion than a definitive finding from the study, one should be mindful that it could occur.

II. Gaps in coverage

a. Gaps within sub-domains assessed by the SF-36

Where the impact of survivors' personal status is concerned, the SF-36 only captures the following in a consistent manner:

- Mutual effects exerted by physical status, emotional/psychological status and cognitive status on one another.
- Effects exerted by physical status on activities and behaviours.
- Effects exerted by emotional/psychological status on activities and behaviours.

However, while the SF-36 does capture some of the effects in the above sub-domains, not all the effects within these sub-domains are covered adequately.

Regarding the mutual effects exerted by the various aspects of personal status on one another, it has already been stated earlier that emotional/psychological consequences and cognitive consequences are not always captured, especially, cognitive consequences.

When it comes to the assessment of the impact of physical status on activities and behaviours, there are two main issues in SF-36's capture of this sub-domain. First, as already mentioned, the SF-36 does not distinguish between the impact of physical status and that of emotional/psychological status on social activities.

Second, the SF-36 does not capture the full impact of physical status on activities and behaviours. It does not ask about all the activities and behaviours that have been mentioned by study participants as being affected by their physical status. In addition, it only assesses restrictions in activities and behaviours, when survivors' physical status can lead to increases in their activities and behaviours.

With respect to the SF-36 not assessing all the activities and behaviours affected by survivors' physical status, some of the activities and behaviours not captured are within the groups of activities and behaviours already covered by the SF-36 while others are not covered by the SF-36 at all.

In terms of the gaps within the groups of activities and behaviours already assessed by SF-36, the activities and behaviours not assessed mainly fall within personal posture and mobility, and self-care activities. The gaps are significant, as the activities and behaviours captured within these two groups of activities and behaviours cannot be used as proxies for activities and behaviours that are not assessed. For instance, participant 03 could walk a considerable distance but struggled with hand grip. Participant 12 could wash herself but all her toileting activities were done by her husband. She said, "I can't do this myself, my husband has to empty and put clean bags on for me because it's just impossible for me to do it myself.". This was because after her critical illness, she required a transverse loop colostomy, and its position meant she could not attend to her toileting needs herself.

Furthermore, the activities and behaviours assessed by the SF-36 within these two groups of activities and behaviours cover a narrower spectrum of physical capacity than those reported as affected by study participants. Within personal posture and mobility, the activities and behaviours discussed by participants as affected indicated that their physical status at the time of hospital discharge was at a much

lower level than the questions in the SF-36 were aiming at. Therefore, significant floor effects would be seen when the SF-36 is used in survivors to assess the impact of physical status on this group of activities. Study participants could be so weak when they were first discharged that gripping a pen or opening a Tupperware container was a struggle⁶⁴. As participant 05 pointed out, he was struggling with activities which required minimal physical effort such as working a lighter or getting the top off a jar right at the beginning of his recovery. To truly capture what he was like when he was first discharged, questions would have to be asked about activities that seem to require very little physical effort. With this in mind, the gaps pertaining to activities such as hand grip and hand dexterity are particularly significant.

As for self-care activities, the activities and behaviours mentioned by survivors as affected but not assessed by the SF-36 required either a higher or lower level of physical capacity than ones already covered by the SF-36. For example, feeding oneself, eating and drinking would require less physical fitness compared with washing/dressing while many of the individual activities within the subgroup 'looking after his/her own health' (such as attending medical appointments including getting there, and engaging in physical exercise and sports) would require more physical effort. In such a case, both floor and ceiling effects would be seen when survivors' ability to carry out this group of tasks is being measured by the SF-36. Therefore, to attain better discrimination between survivors, additional questions specifically directed at the self-care activities not assessed by the SF-36 would need to be asked.

Besides gaps within groups of activities and behaviours already covered in the SF-36, some of the (groups of) activities and behaviours raised by survivors as being affected by their physical status are (groups of) activities and behaviours that the SF-36 does not assess. These are:

- Using transport (examples are taking a bus, riding in a car as a passenger and using a train).
- Driving (which includes driving a car and riding a bike).

⁶⁴ There is a caveat when saying that small tasks such as gripping a pen require a lower level of physical functioning than say, lifting and carrying groceries. This statement only applies when it pertains to strength and stamina. In certain cases, participants were unable to grip an object because of other reasons, such as joint stiffness. Under such circumstances, participants were able to perform activities that required a higher level of physical functioning, like walking long distances, but unable to grip objects (a physically less demanding activity). This was the case for participant 03; she was able to walk a considerable distance, but could not open a jar. Whatever the case, the fact remains that seemingly very small tasks can pose as challenges for survivors. This point is raised only to explain why in certain cases, the pattern of limitation can appear confusing or even contradictory.

- Sleep/rest.
- Communication with others.
- Recreational and leisure activities.
- Sexual activity (including physical contact with partner).

One can of course argue that the changes in these (groups of) activities and behaviours may be picked up by the existing questions on (groups of) activities and behaviours in the SF-36. For example, for some survivors, driving had constituted part of their working lives, and therefore, the impact of physical status on driving would be picked up by Question 4 of the SF-36 (this question assesses activities associated with societal roles and thus, includes work.) in such survivors. Other survivors, such as participants 03 and 10, included recreational and leisure activities within their interpretation of Questions 3 and 4. However, as already discussed in Section 8.4.1B, Subsection 1, such situations were dependent on individual circumstances and interpretation, and did not happen consistently. As such, if the impact of a person's physical status on these (groups of) activities and behaviours were to be captured consistently, additional questions would have to be asked. The importance of asking these additional questions was highlighted by survivors themselves, as shown in the case of participant 05, who specifically said during his 'questerview' that assessing his ability to use transport should be part of the assessment of his HRQoL.

Other than not assessing all the (groups of) activities and behaviours affected by survivors' physical status, the SF-36's capture of this sub-domain has another significant omission, as already stated. The SF-36 only asks about restrictions in activities and behaviours when the interview data indicate that survivors' physical status can result in increases in their activities and behaviours. For example, many participants felt very fatigued and thus, slept a lot. Some participants also talked about having to take a lot more medication because of their physical status. Although the former may be captured by the questions on whether activities and behaviours are being limited (given that sleeping more would equate to doing less), it is unlikely that the existing questions in the SF-36 would capture the latter case.

With regard to the SF-36's coverage of the impact of emotional/psychological status on activities and behaviours, it has much the same problems as those seen in its assessment of the impact of physical status on activities and behaviours. As already stated, it does not separate the impact of emotional/psychological status from that of physical status on social activities. Furthermore, it does not fully capture the impact of emotional/psychological status on activities and behaviours.

In terms of the SF-36 not covering the impact of emotional/psychological status on activities and behaviours completely, it does not, first of all, capture all the (groups of) activities and behaviours affected by survivors' emotional/psychological status. The (groups of) activities and behaviours that are not usually captured by the SF-36 include personal posture and mobility, using transport, driving, sleep/rest, communication with others, self-care activities, recreational and leisure activities and sexual activity.

While the study data do indicate that the SF-36 may capture the impact of emotional/psychological status on some of the aforementioned (groups of) activities and behaviour such as personal posture and mobility, driving, self-care activities and recreational and leisure activities (detailed discussion in Section 8.4.1B, Subsection I), this is subject to the individual circumstances and cognitive processes of the survivor completing the questionnaire and does not happen consistently.

In addition, even when the SF-36 does capture the impact of emotional/psychological status on (groups of) activities and behaviours like personal posture and mobility and self-care activities, it does so incompletely. This is because the SF-36 does not examine all personal posture and mobility activities and self-care activities affected by survivors' emotional/psychological status. For instance, some survivors interviewed spoke about how their emotional/psychological status had made them fearful of seeking medical attention (which would be classified under 'looking after his/her own health' within self-care activities) but the SF-36 does not assess this particular self-care activity. Therefore, all in all, it should not be assumed that the SF-36 consistently captures the effects of emotional/psychological status on these (groups of) activities and behaviours.

Second of all, the SF-36, again, only evaluates restrictions in activities and behaviours caused by survivors' emotional/psychological status even though the evidence show that increases in activities and behaviours can also occur secondary to survivors' emotional/psychological status. For instance, participant 24, because of her worries about falling sick again, was obsessed with cleaning and spoke about cleaning her hands a lot more often. Participant 07 spoke about increasing her family social activities because of her change in priorities after her critical illness. Although some of these increases in activities and behaviours such as participant 24's recurrent handwashing may end up interfering with their other activities and behaviours, and thus be ultimately viewed as restrictions, the way survivors spoke about these activities was not as restrictions. Rather, they simply stated that they had increased

certain activities and behaviours. Therefore, it is entirely possible that such increases in activities and behaviours induced by emotional/psychological status are not captured by the SF-36.

b. Sub-domains not assessed by the SF-36

From the above discussion, it is clear that the SF-36 has gaps in coverage in terms of the following effects exerted by survivors' personal status:

- Mutual effects of the various aspects of survivors' personal status, notably emotional/psychological consequences and cognitive consequences.
- The impact of physical status on activities and behaviours.
- The impact of emotional/psychological status on activities and behaviours.

Besides these gaps, the SF-36 also has other significant omissions in terms of its evaluation of the impact of survivors' personal status. The assessment of personal status on activities and behaviours is incomplete in that none of the questions in the SF-36 are aimed at capturing the effects exerted by cognitive status. In addition, the SF-36 does not have any direct questions designed to capture the effects of survivors' personal status in the following sub-domains:

- Perception of, interpretation of, and responses to life.
- Personality.
- External appearance.
- Physical zone of comfort and/or activity.
- Suitability and availability of clothes.
- Interactions and relationships with others.
- Place of residence.
- Finances.

Despite the fact that the SF-36 does not directly cover the above effects, one can argue that the SF-36 may still cover some of these effects by capturing them indirectly and/or inadvertently with the existing questions in the questionnaire. Whether this is indeed the case is first reviewed in the context of the impact of cognitive status on activities and behaviours before the same examination is performed for the effects of personal status on the sub-domains of 'perception of, interpretation of, and responses to life', 'personality', 'external appearance', 'physical zone of comfort and/or activity', 'suitability and availability of clothes', 'interactions and relationships with others', 'place of residence' and 'finances'.

In terms of whether (some of) the existing questions in the SF-36 capture the impact of cognitive status on activities and behaviours, Question 3 of the SF-36 asks

about how activities and behaviours are affected by health in general without specifying a particular aspect of health. Therefore, although this question is meant to capture how a person is from a physical point of view, it may pick up the effects of cognitive status on activities and behaviours. This is because cognitive status also affects the activities and behaviours asked about in Question 3. In addition, the way cognitive status affects activities and behaviours may be through its impact on physical status and emotional/psychological status. In such cases, the impact of cognitive status on activities and behaviours would essentially be correlated with the effects that physical status and emotional/psychological status have on activities and behaviours, which are both assessed by the SF-36.

However, there are arguments against the SF-36 satisfactorily capturing the impact of cognitive status on activities and behaviours with its current questions. The way cognitive status affects activities and behaviours is often different from what is being asked in Question 3. For instance, Question 3 asks about the distance a person can walk, whereas changes in survivors' cognitive status affected their walking by causing them to bump into things. As participant 13 said, he had become very much poorer at judging spaces and distances, and hence, was constantly walking into objects. Therefore, Question 3, because it is not asking the right questions, will give limited insight into the impact of a person's cognitive status on personal posture and mobility and self-care activities.

Furthermore, the correlation of cognitive status with physical status and/or emotional/psychological status varies across survivors. At present, there is no way of predicting whether these correlations exist for a particular survivor, and, if so, the degree to which it occurs. Therefore, there is no way of using the answers to the questions capturing the effects of a survivor's physical status and emotional/psychological status to provide an accurate estimation of the impact of his/her cognitive status.

Finally, as already stated, the way the SF-36 asks about activities and behaviours is to enquire purely about restrictions in carrying out activities. In contrast, survivors interviewed spoke about how poor cognitive status led to an increase in certain activities and behaviours. For instance, participant 13 talked about how frustrated he was to have to keep checking that he had switched off his cooker. Such increases in activities and behaviours are not looked at specifically by the SF-36 and may not be captured by the questionnaire. However, if the particular survivor completing the questionnaire sees such increases in activities and behaviours as an

obstacle to carrying out their other activities (which then translates into a limitation in activity), it may be captured by the questions enquiring about limitations. Unfortunately, this scenario was not specifically explored with study participants and as such, the argument cannot be definitively confirmed or refuted. Therefore, not capturing increases in activities and behaviours should still be considered a potential limitation in the ability of the SF-36 to capture the effects of cognitive status on activities and behaviours indirectly.

With regard to whether the SF-36 indirectly captures some of the effects of personal status in the rest of the sub-domains (perception of, interpretation of, and responses to life; personality; external appearance; physical zone of comfort and/or activity; suitability and availability of clothes; interactions and relationships with others; place of residence; and finances), it is possible that this does occur. This is because the effects within some of these sub-domains are related to survivors' activities and behaviours, which is captured by the SF-36. However, such relationships are not straightforward, and to say that capturing the changes in activities and behaviours would consistently and reliably capture the effects within the other sub-domains would be an over-simplification. For example, while a survivor's activities and behaviours help determine where they would stay after their illness, it is but one of the factors involved. Solely assessing what a survivor can or cannot do would not accurately predict where they would end up residing. Participant 22 was physically very disabled after his critical illness; he could not even turn himself in bed. However, he could return home after discharge because his wife was there to look after him whereas other survivors who were physically better off than him had to stay somewhere else before returning home because they had less support at home.

Furthermore, the activities and behaviours associated with the effects in these sub-domains are often not the same as those being assessed by the SF-36. For instance, participant 25's hairstyle as well as the colour of her hair had changed following her critical illness (change in external appearance). This was because she was unable to visit a hairdresser due to her irrational fears after her illness. Although the change in her external appearance was related to her not doing a specific activity (in this case, not going to the hairdresser), the activity (going to the hairdresser) is neither one that is directly assessed by the SF-36 nor is it an activity that has a predictable relationship with any of the other activities assessed by the SF-36.

Therefore, even though some of the sub-domains not assessed by the SF-36 are linked to activities and behaviours, which are assessed by the questionnaire, the

nature of these links are such that on balance, activities and behaviours cannot be used as a surrogate for such sub-domains. This, in turn, means that these sub-domains should be treated as not being captured by the SF-36. This, coupled with the fact that sub-domains not linked to activities and behaviours (for example, suitability and availability of clothes) are definitely not captured by the SF-36, means that the SF-36 does not cover many of the consequences resulting from survivors' personal status.

All in all, when it comes to the impact of survivors' personal status, the SF-36 only manages to capture consistently:

- Some of the mutual effects of physical status, emotional/psychological status and cognitive status. Physical consequences are particularly well captured compared to emotional/psychological and cognitive consequences
- The restrictive effects of physical status on activities associated with societal roles and social activities as well as some of its restrictive effects on personal posture and mobility and self-care activities.
- The restrictive effects of emotional/psychological status on activities associated with societal roles and social activities.

In contrast, it does not always and/or adequately cover:

- Some of the mutual effects of physical status, emotional/psychological status and cognitive status, especially the emotional/psychological consequences and cognitive consequences.
- Some of the effects of physical status and emotional/psychological status on activities and behaviours. Some of the effects that are not captured are restrictive while others involve increases in activities and behaviours.
- Effects of cognitive status on activities and behaviours.
- Effects of personal status on:
 - Perception of, interpretation of, and responses to life.
 - Personality.
 - External appearance.
 - Physical zone of comfort and/or activity.
 - Suitability and availability of clothes.
 - Interactions and relationships with others.
 - Place of residence.
 - Finances.

The SF-36 neither assesses many of these consequences directly nor captures them accurately through their relationships with the sub-domains assessed.

This concludes the discussion on the extent to which the SF-36 captures the domains and sub-domains of the patient-based framework. The next subsection assesses how well the other expert consensus generic measure, the EQ-5D, covers survivors’ HRQoL using the same framework.

8.4.2. Content mapping between the EQ-5D and the patient-based conceptual framework

The EQ-5D consists of a descriptive system and a visual analogue scale (Table 8.3).

Table 8.3: Questions of the EQ-5D

<p>Descriptive system</p> <p>By placing a tick in one box to each group below, please indicate which statements best describe your own health state today.</p> <div><div>1. Mobility.</div><div>2. Self-care.</div><div>3. Usual activities (e.g. work, study, housework, family or leisure activities).</div><div>4. Pain/discomfort.</div><div>5. Anxiety/depression.</div></div> <p>Visual analogue scale</p> <p>To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worse state you can imagine is marked 0.</p> <p>We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.</p>
--

The descriptive system covers how a person’s health state affects:

- Mobility (specifically walking).
- Self-care (specifically washing and dressing).
- Usual activities (from the examples given, this category is meant to capture activities which have been classified as ‘activities associated with societal roles’, ‘social activities’ and ‘recreational and leisure activities’, in this thesis)
- Pain/discomfort (i.e. physical status).
- Anxiety/depression (i.e. emotional/psychological status).

The visual analogue scale then asks an individual to score his/her own overall health.

The rest of this subsection assesses how well this measure captures the important conceptual domains and sub-domains of survivors' HRQoL.

A. Capture of survivors' personal status

The EQ-5D is very similar to the SF-36 when it comes to capturing survivors' personal status. It contains questions that are specifically designed to cover physical status and emotional/psychological status but none of its questions are aimed at assessing cognitive status. Nonetheless, cognitive changes may still be captured.

Given that the EQ-5D and SF-36 share many of the same qualities in terms of coverage of survivors' personal status, much of the discussion surrounding the SF-36 also applies here. Where this is the case, the pertinent points will be explored in a brief manner. For more details, please refer to the corresponding section on the SF-36 above.

I. Domains which are captured

The visual analogue scale in the EQ-5D is similar to the questions asking about general health perceptions in the SF-36. It may capture all three conceptual domains of survivors' personal status, but this does not always occur. This is because the scale allows survivors to define the term 'health state' themselves, which gives them a degree of flexibility. Survivors' definition of this term can vary from including all three conceptual domains to including only physical status, with the domain(s) captured corresponding to this definition.

Given that survivors' individual definition of the term 'health state' determines the domains captured, this scale, in general, universally captures the domain of physical status. However, there is evidence to show that not every single physical change suffered by survivors consequent to their illness is captured within the definition of 'health state' and thus, this scale may not capture the domain of physical status in its entirety at all times.

In contrast to the situation with the domain of physical status, the domains of emotional/psychological status and cognitive status are less consistently captured. Study data show that survivors do not always include these domains in their definition of health. Survivors such as participants 01, 07 and 20 were all examples of such survivors.

Besides the visual analogue scale, the EQ-5D also has other questions, Questions 4 and 5, that address specific aspects of physical status and emotional/psychological status. Question 4 asks about pain/discomfort (physical status) while Question 5 enquires about anxiety/depression (emotional/psychological

status).

In asking about pain/discomfort, Question 4 captures a particular aspect of physical status that is relevant for survivors. This is because pain/discomfort can be a significant problem for some survivors. For instance, it was the first thing participant 05 talked about during his interview.

However, as already reported earlier, even though pain is of definite relevance to some survivors, it is no more important than many other physical changes experienced by survivors. It is often not the most challenging physical change for many survivors. For instance, for participants 08 and 23, fatigue and incontinence were the physical changes that took precedence for them, and accordingly, the lack of evaluation of fatigue and incontinence by the EQ-5D were pointed out as gaps by participants 08 and 23, respectively. Moreover, it does not appear to occur more frequently in survivors than other physical problems. If anything, fatigue, being almost universal, appears to be survivors' most frequent complaint. Thus, although pain is assessed specifically, it is by no means the most significant physical change for survivors.

As for Question 5, it enquires about anxiety/depression, two prominent emotional/psychological changes that occur in survivors. Again, similar to the case pertaining to the significance of pain in survivors' physical status, these two changes are relevant to (some) survivors' emotional/psychological status but they are no more important and prominent than many other emotional/psychological changes experienced by survivors (See Chapter 5, Table 5.2 for more details of these changes.). For instance, participant 19 had had flashbacks since her critical illness and this emotional/psychological problem had affected her significantly enough for her to say that the EQ-5D, in not assessing it, had a gap in terms of coverage of her HRQoL. In participant 13's case, increased self-consciousness was one of his prominent emotional/psychological issues, and he pointed out, during the 'questerview', that this should be assessed in a HRQoL questionnaire.

Furthermore, in comparison to anxiety and depression, some of the other emotional/psychological changes that survivors experienced appear to be more specific to the critical illness experience and recovery. Examples of such changes include: intrusive memories and flashbacks; nightmares; and irrational beliefs and phobias. Therefore, while anxiety and depression are relevant and specifically evaluated in the EQ-5D, they are not the only emotional/psychological changes that are of importance to survivors.

In summary, the EQ-5D consistently captures:

- An overview of physical status, alongside the specific aspect of pain.
- Two specific aspects of survivors' emotional/psychological status, anxiety and depression.

Subject to survivors' definition of 'health state', the EQ-5D may also capture:

- An overview of emotional/psychological status.
- An overview of cognitive status.

II. Gaps in the capture of survivors' personal status

The EQ-5D has gaps in coverage of survivors' personal status because the questions do not consistently and/or completely capture the domains of emotional/psychological status and cognitive status.

Regarding the assessment of emotional/psychological status, it has already been stated that the visual analogue scale in the EQ-5D does not consistently capture an overview of survivors' emotional/psychological status. In addition, the EQ-5D does not specifically ask about any changes other than anxiety and depression. Given that the visual analogue scale does not consistently capture an overview of survivors' emotional/psychological status, the lack of specific questions on emotional/psychological changes outside those on anxiety and depression means that the EQ-5D may not always capture all emotional/psychological changes of importance to survivors.

In terms of the conceptual domain of cognitive status, the EQ-5D does not directly capture this domain in a consistent way. As already discussed earlier, the visual analogue scale captures survivors' cognitive status only when their definition of 'health status' includes this domain. In addition, the EQ-5D does not have any questions that specifically assess the cognitive changes that occur in survivors [contrast this with Question 4 of the EQ-5D which asks specifically about pain/discomfort, (physical status), and Question 5 which looks at anxiety/depression (emotional/psychological status)]. There are no questions expressly addressing cognitive areas such as concentration, memory, language or executive function. This lack of direct assessment of cognitive status in the EQ-5D is supported by the fact that some study participants asserted, with some prompting, that the EQ-5D did not assess cognitive status. Of course, such survivors could have been agreeing out of politeness. Nonetheless, judging by how they went on to elaborate on how the EQ-5D did not adequately capture cognitive status, some of these survivors must have genuinely believed that this domain was not well covered by the EQ-5D.

Although the EQ-5D does not directly and/or specifically address cognitive changes, one can still argue that it captures some cognitive changes indirectly. Question 5 of the EQ-5D evaluates anxiety/depression and the study data has indicated that these emotional/psychological changes could be linked to cognitive changes such as poor memory and executive dysfunction. With such a correlation, the answer to this question could be a surrogate for the individual's cognitive status. On the other hand, using the answer to this question as a marker of cognitive status is unreliable at best. This is because cognitive changes are not always correlated with these emotional/psychological changes. In addition, when a correlation does exist, the degree to which it does so varies from survivor to survivor.

Therefore, not only does the EQ-5D not contain any direct and specific questions on cognitive changes, it does not consistently capture such changes indirectly either. Given such a scenario, it would not be unreasonable to conclude that the EQ-5D does not capture the conceptual domain of cognitive state in a satisfactory manner.

B. Coverage of the impact of survivors' personal status

There are questions in the EQ-5D that address the impact of survivors' personal status. These questions look at the effects exerted by survivors' health in general (versus the effects exerted by each aspect of health).

I. Effects captured by the EQ-5D

It has already been highlighted in Section 8.4.2A, Subsection I that the visual analogue scale and Questions 4 and 5 in the EQ-5D cover (at least part of) the conceptual domains making up survivors' personal status. They will therefore capture some of the mutual impact that physical status, emotional/psychological status and cognitive status exert on one another. Again, as already discussed, these questions capture physical status, emotional/psychological status and cognitive status to different degrees. Consistent with this discussion (in Section 8.4.2A, Subsection I), physical consequences will be best captured, followed by emotional/psychological consequences and then cognitive consequences. Furthermore, if the mutual effects include pain, anxiety and depression, such consequences will always be captured, given that Questions 4 and 5 are specifically aimed at these changes.

Besides questions that capture these mutual effects exerted by various aspects of personal status, the EQ-5D also contains questions addressing the impact of survivors' personal status on (some of) their activities and behaviours. These are Questions 1-3 and they look at how health, as a whole, affects certain (groups of)

activities and behaviours, namely:

- Mobility, specifically walking.
- Self-care, specifically washing and dressing.
- Usual activities (examples of usual activities given in the EQ-5D are work, study, housework, family and leisure activities).

These questions, like the visual analogue scale, do not specify the definition of 'health state', but instead, allow survivors the freedom to define the term themselves. Therefore, in survivors who view 'health state' as encompassing their physical status, emotional/psychological status and cognitive status, the effects of physical status, emotional/psychological status and cognitive status on these (groups of) activities and behaviours would be captured.

However, there are survivors whose concept of 'health state' is not quite as broad. In these survivors, there will be correspondingly fewer effects captured. The effects covered will be those within the domains survivors see as part of their 'health state'.

As physical status is the only conceptual domain that is always viewed as part of 'health state', it follows that the only effects consistently captured by Questions 1-3 are the impact of physical status on the (groups of) activities and behaviours mentioned in these questions. Emotional/psychological status and cognitive status are not always viewed as part of the term 'health state', and therefore, correspondingly, their effects on these (groups of) activities and behaviours will not always been captured by Questions 1-3.

II. Gaps in coverage

a. Gaps within the sub-domains assessed by the EQ-5D

When it comes to the impact of survivors' personal status, the only effects that EQ-5D always captures are:

- Mutual effects of physical status, emotional/psychological status and cognitive status on one another. In particular, pain, anxiety and depression, should they be part of the consequences of other aspects of survivors' personal status, will always be covered.
- Impact of physical status on activities and behaviours.

Nonetheless, not all effects within these sub-domains are captured by the EQ-5D.

As already discussed, the EQ-5D does not always capture all the mutual effects caused by various aspects of survivors' personal status. Depending on survivors'

definition of 'health state', emotional/psychological consequences (other than anxiety and depression) and cognitive consequences are sometimes not captured.

Where the impact of physical status on activities and behaviours is concerned, there are two main omissions. First, not all the activities and behaviours raised by survivors as being affected by their physical status are covered by the (groups of) activities and behaviours mentioned in the EQ-5D. The groups 'mobility' and 'self-care' should assess more than just 'walking' and 'washing and dressing' respectively. The group 'mobility', for example, should include many more activities when it comes to survivors, from hand grip to maintaining an upright posture to transfer activities. In fact, participant 19 specifically pointed out during her 'questerview' involving the EQ-5D that whilst walking was important, transfer activities were just as important to assess. As 'walking' within the group of 'mobility' and 'washing/dressing' within the group of 'self-care' are not related to the other activities within their respective groups, they cannot be used as surrogate measures for these other activities.

Furthermore, the study data show that 'walking' (mobility) and 'washing/dressing' (self-care) capture a spectrum of physical capacity that is much narrower than the activities and behaviours reported as affected by survivors. As an illustration, when survivors were talking about their mobility, hand grip and running were both activities survivors spoke about as being affected. Hand grip requires a lesser level of physical capacity compared with walking while running requires a higher level of physical capacity than walking. That being the case, to capture these groups of activities and behaviours in a more complete manner conceptually and to discriminate between survivors more effectively, activities other than walking and washing/dressing would have to be assessed for the groups 'mobility' and 'self-care activities'. In not assessing these other activities within the two groups 'mobility' and 'self-care', the EQ-5D exhibits a gap in coverage where the evaluation of the impact of physical status on activities and behaviours is concerned.

As for the group 'usual activities', it is so broadly defined that it would not be unreasonable to answer the question relating to the group as if it contains all the other activities that cannot be readily classified under the groups 'mobility' and 'self-care'. Nonetheless, the study data have shown that a number of the survivors interviewed did not quite see it that way. Survivors such as participants 13 and 19 listed the absence of evaluation in sleep/rest, communication with others and sexual activity as gaps in the questionnaire, indicating that some survivors did not think that all the (groups of) activities and behaviours relevant for them were being assessed.

Ultimately, the exact (groups of) activities and behaviours not captured will depend on how survivors define the term 'usual activities' and this will differ between survivors.

Second, only limitations of activities and behaviours resulting from survivors' physical status are assessed. In some cases, participants' physical status led to increases in activities and behaviours. For instance, participant 10 had to take a lot more medication than she had had to before. Whilst increases in certain activities and behaviours such as sleeping more might be captured indirectly by assessing limitations in activities and behaviours, not all increases in activities and behaviours would be captured in a similar manner. Therefore, with the EQ-5D not directly assessing increases in activities and behaviours, certain effects caused by physical status in activities and behaviours would not be captured.

b. Sub-domains not assessed by the EQ-5D

Besides not covering all the effects within the sub-domains that it always captures, the EQ-5D also lacks coverage of many other consequences brought about by survivors' personal status.

First, the impact of emotional/psychological status and cognitive status on activities and behaviours may not always be captured. Although it was not specifically explored with survivors during their 'questerview' whether they did or did not incorporate the difficulties caused by their emotional/psychological status and cognitive status into their answers, there were participants who see 'health' as referring simply to physical status. It would, therefore, not be unreasonable to assume that, for these same survivors, only the effects of their physical status were considered to be part of the consequences imposed on them by their health state. In such survivors, the effects of emotional/psychological status and cognitive status on activities and behaviours would not be captured.

Second, even when emotional/psychological status and cognitive status are within survivors' definition of 'health state' with consequent capture of their effects in activities and behaviours, the EQ-5D would still not capture their full impact on activities and behaviours. Similar to the case with physical status, both emotional/psychological status and cognitive status affect more (groups of) activities and behaviours than those assessed by the EQ-5D. For example, in the group 'mobility', emotional/psychological changes (lack of confidence) also affected climbing stairs and cognitive changes (disruption of procedural memory) also disrupted hand dexterity. In comparison, the EQ-5D only assesses walking. Similarly, in 'self-care', the EQ-5D only assesses washing and dressing whereas both

emotional/psychological status and cognitive status also affected participants' attendance at medical appointments. As for the group 'usual activities', it should theoretically capture all the remaining activities that do not fall into the groups of 'mobility' and 'self-care'. However, the reality is that a number of participants did not perceive it that way. For example, participant 13 cited communication with others and sexual activity as two examples of activities not captured by the EQ-5D, but affected by his emotional/psychological status.

Furthermore, as already said, the EQ-5D only assesses restrictions in activities and behaviours whereas study participants spoke about increases in certain activities and behaviours brought about by either emotional/psychological status or cognitive status. For instance, participant 24 was obsessed about washing her hands and her surroundings because of worries of falling ill again and participant 13 engaged in recurrent checking behaviour to ensure that he had not forgotten anything. Although some of these activity and behavioural increases may be viewed as limitations (such as recurrent checking behaviours in participant 13's case) and thus, captured by the EQ-5D, not all instances of increased activities and behaviours may be seen as such. Therefore, in assessing only restrictions, the EQ-5D would not capture all the effects resulting from emotional/psychological status and cognitive status.

Finally, the EQ-5D does not contain any questions aimed at capturing the effects of survivors' personal status in the following sub-domains:

- Perception of, interpretation of, and responses to life.
- Personality.
- External appearance.
- Physical zone of comfort and/or activity.
- Suitability and availability of clothes.
- Interactions and relations with others.
- Place of residence.
- Finances.

Some may of course argue that although the EQ-5D does not have any questions addressing these sub-domains, it does capture the effects in some of them, if only in an indirect manner through its assessment of survivors' activities and behaviours. This is because some of these sub-domains are related to survivors' activities and behaviours.

However, these relationships are not straightforward. For instance, participants' activities and behaviours were but one of the factors that helped

determine where they lived. Moreover, the activities and behaviours that the changes in these sub-domains are related to are often not the same activities and behaviours assessed by the EQ-5D. For example, certain changes in external appearance were due to changes in grooming activities, which are not assessed by the EQ-5D. Therefore, the results of the assessment of survivors' activities and behaviours cannot simply be extended to these other sub-domains even when there are links between them.

As for sub-domains such as 'suitability and availability of clothes' that have no consistent relationship with activities and behaviours, there is no doubt that they are not captured by the EQ-5D.

In summary, of all the consequences of survivors' personal status, the following are always captured by the EQ-5D:

- Some of the mutual effects physical status, emotional/psychological status and cognitive status exert on one another. Physical consequences are captured most consistently whereas emotional/psychological and cognitive consequences are less well covered.
- Some of the restrictive effects physical status has on certain activities and behaviours.

In comparison, the EQ-5D either does not consistently capture or does not capture at all the following consequences of survivors' personal status:

- Some of the mutual effects of physical status, emotional/psychological status and cognitive status. In particular, emotional/psychological consequences and cognitive consequences are not always captured.
- Some of the effects exerted by physical status on activities and behaviours. Some of the effects involve restrictions in activities while others are increases in activities.
- Some or all of the effects exerted by emotional/psychological status and cognitive status on activities and behaviours.
- Effects exerted by personal status on:
 - Perception of, interpretation of, and responses to life.
 - Personality.
 - External appearance.
 - Physical zone of comfort and/or activity.
 - Suitability and availability of clothes.
 - Interactions and relationships with others.

- Place of residence.
- Finances.

8.5. Conclusion

The research work described in this chapter is carried out to gather information on the gaps of coverage in the expert consensus generic measures where survivors' HRQoL is concerned. This knowledge helps with recommendations on the possible domains and sub-domains to be included in a critical care-specific measure, such that there is minimal duplication of domains (and sub-domains) assessed in the generic and specific measures. This is important, as survivors tend to be frail and respondent burden is a major consideration.

To facilitate the above process, the findings of the preceding empirical chapters (Chapters 4-7) were drawn on to finalise a patient-based conceptual framework for the HRQoL of survivors at the start of the chapter. This framework summarises the domains and sub-domains that need to be assessed if survivors' HRQoL were to be captured. The framework, alongside detailed findings on its various components, was then compared against the content of the current recommended generic measures for survivors, the SF-36 and EQ-5D, so as to identify the domains (and sub-domains) that are not well covered by these two measures. In addition, survivors were also asked to complete either the SF-36 or the EQ-5D, after which they were invited to share their thoughts on whether they felt that these measures captured their health and QoL, including their opinion on gaps of coverage in these measures.

Using these methods, it has been ascertained that the content of the SF-36 and EQ-5D does not adequately cover the two components of the conceptual framework, survivors' personal status and the impact of survivors' personal status. A summary of the notable gaps is, as follows:

- Both SF-36 and the EQ-5D capture survivors' personal status to some extent. Physical status is best captured while cognitive status is least well captured. Coverage of emotional/psychological status falls between the two. This incomplete coverage of survivors' emotional/psychological and cognitive statuses by the SF-36 and EQ-5D is significant. From the interview data, it was clear that, generally, survivors' emotional/psychological and cognitive status were important to them. In addition, many of the study participants experienced considerable emotional/psychological and cognitive changes. Therefore, the domains (and sub-domains) of emotional/psychological status

and cognitive status should be included in a specific measure.

- Both the SF-36 and EQ-5D only evaluate a small part of the impact of survivors' personal status. Besides some of mutual effects exerted by various aspects of personal status on one another, and some of the effects in relation to activities and behaviours, the rest of the consequences incurred by survivors' personal status are inconsistently captured or not captured at all. Again, similar to the situation with respect to capturing all aspects of survivors' personal status fully, many of these consequences, such as changes in external appearance, suitability and availability of clothes, and changes in place of residence, were of significant importance to study participants and thus, need to be captured. This, in turn, means that these consequences of survivors' personal status should be assessed in a specific measure.

In summary, there are a number of gaps of coverage in the SF-36 and EQ-5D in terms of the important domains and sub-domains of survivors' HRQoL. Accordingly, the domains and sub-domains missing from the SF-36 and EQ-5D should be included in a critical care-specific measure. By having the specific measure assess the domains and sub-domains not covered by the SF-36 and EQ-5D, two important goals are achieved simultaneously. It helps obtain a (more) complete picture of how critical illness affect survivors' QoL. At the same time, in keeping the content of the specific measure complementary to that of the generic measures used, it avoids having survivors cover the same concepts twice and in this way, reduces respondent burden.

With the elucidation of the domains and sub-domains that are particularly important to include in a critical care-specific measure, it is time to pay attention to some of the other considerations concerning the content of such a measure. These considerations are the focus of the next chapter.

Chapter 9: Other considerations in relation to the content of a critical care-specific measure

9.1. Introduction

The study helped clarify the domains and sub-domains that need to be included in a specific measure for survivors. In addition, the data collected also highlighted a number of other issues that have implications for the content of such a measure. Some of these issues were pointed out by the study participants themselves while others were concluded from examining the findings of the study. This chapter concentrates on such issues.

First, the methods used to identify these issues are outlined, followed by a discussion on these issues.

9.2. Methods used to identify concerns that have relevance for the content of a critical care-specific measure

Thematic analysis of the data collected during the 'questerview' component was performed with the following emphasis: to identify how the content of a standardised questionnaire (other than the domains and sub-domains being assessed) can contribute to pitfalls in the assessment of survivors' HRQoL.

In addition, the findings of this analysis were supplemented by the challenges highlighted when constructing the final, patient-based conceptual framework for survivors' HRQoL. Having the content of a questionnaire capture survivors' HRQoL is similar to building the final, patient-based conceptual framework to reflect survivors' HRQoL in that both processes seek to accurately represent survivors' HRQoL. Therefore, insights into the challenges encountered during the construction of the framework help with understanding the areas that need attention when considering the content of a questionnaire.

9.3. Other concerns that have implications for the content of a critical care-specific measure

As already stated, besides establishing the domains and sub-domains that need assessment in a critical care-specific measure, the study also yielded information on other important considerations that are pertinent to the content of such a measure. This section explores these considerations in detail.

9.3.1. The importance of capturing survivors' perceptions

To further improve the measurement of survivors' HRQoL, it is important to consider specifically capturing survivors' perceptions in a critical care-specific measure, particularly when the items within the measure are standardised. This is

because the characteristics of the critical care population, alongside the process of adaptation, makes it challenging for a (standardised) measure to effectively represent survivors while retaining a high degree of relevance at the same time.

The heterogeneity of the critical care population⁶⁵ creates an inherent tension between representing survivors collectively as a population and representing them individually. For a measure to truly reflect the entire critical care population, the (standardised) items within the measure have to cover a wide spectrum. However, covering a wide spectrum makes it more likely that any given item will not be relevant in the same way, or at all, for everyone. For instance, participant 02, talked about being able to do sport before his critical illness, including running, cycling, swimming, and playing golf, rugby and football. Therefore, although he was doing “a lot of walking” and going to the gym at the time of his interview, this was nowhere near what he had been doing before his critical illness, and he was frustrated about that. In comparison, participant 15 was walking with crutches even before his critical illness and even then, he could not walk very far. He did do some swimming, but the level of sports activities he engaged in was far below what participant 02 was involved in. To capture the full range of what is important to these two survivors in this particular area, the ability to do very vigorous sports would have to be assessed as it is clear that participant 02 wanted to be able to do that. However, this was not very relevant to participant 15 given what he was like before his critical illness.

Besides, the process of adaptation, with preceding response shifts in some cases (117), means that it is difficult for a standardised measure to be both representative and relevant even when it is just in the context of a single survivor. The way the adaptation process creates a tension between the representativeness and relevance of a measure is well illustrated by participant 14’s case. After her critical illness, she struggled with climbing stairs, which had previously not been a problem for her. Although she still had to manage stairs on occasions (like in her own home), she had adapted by using lifts and escalators whenever she could. Therefore, for her, to capture all the changes relevant to her in all circumstances (representativeness), climbing stairs would have to be included. However, in reality, the ability to climb stairs had diminishing relevance in her life as she adapted to avoid it. Another example, this time more specifically on how response shift can create a similar

⁶⁵ The heterogeneity of the critical care population exists on many levels, from their personal condition and circumstances, circumstances before critical illness, the cause of their critical illness, to the issues they face after their critical illness.

tension, would be participant 13's case. He experienced a significant deterioration in his personal status after his illness and initially, this affected his sense of well being and QoL significantly. However, over time, he had a response shift and came to a place of acceptance with regard to his poorer personal status and consequent limitations (the relevant quote is in Chapter 5, Section 5.3.1, Page 96 and hence, not repeated here). As a result, the deterioration in his personal status and the restrictions he was experiencing had less impact on his QoL. In order to capture all aspects relevant to participant 13's HRQoL at all times, his personal status and many of the resultant limitations would have to be represented in a measure. However, it is clear that these aspects became less relevant to his HRQoL as he experienced a response shift and adapted to his personal status and the limitations this imposed on him.

From the above discussion, it is clear that there is an inevitable tension between the representativeness of a critical care specific measure and its relevance. While this tension is not unique to the critical care population, it is especially striking in this population. This is mainly because the heterogeneity in this particular population is generally far more prominent than that seen in most other patient populations. With such a marked inherent tension between representativeness and relevance, it is important to consider taking steps to offset the tension for this population (even if only partially), as it will help refine the measurement of survivors' HRQoL.

Capturing perceptions of what is important to the survivors answering the questions is central to the resolution of this tension. This can be achieved in a number of ways. Applying values to health states, such as that seen in preference-based measures, is one way of incorporating these perceptions (17). There are two main methods of applying values to health states, namely, the direct method and the indirect method (17). With the former, individuals are asked to assess and directly value their own health state by using techniques such as the visual analogue scale (VAS), standard gamble (SG) and time trade-off (TTO) (17). In the latter, individuals are asked to complete a relevant health status questionnaire which is then valued indirectly using values obtained from the general population (17). EQ-5D and Health Utilities Index (HUI) are both examples of questionnaires that allow values to be applied indirectly.

Another way of capturing individualized perceptions is to ask individuals to indicate their level of satisfaction and/or concern about given changes, either by using additional questions or by incorporating the query within the questions on the

changes. This is used in a number of questionnaires ranging from the long-form questionnaire used by RAND in the 1980s for the Medical Outcomes Study to more recently developed questionnaires such as the Community-Acquired Pneumonia Symptom Questionnaire (CAP-Sym) and the DEMQOL (specific HRQoL measure for people with dementia) (18, 31, 118). Individualized QoL measures that have a very modest level of individualization such as the SmithKline Beecham Quality of Life Index (SBQoL) also utilize this method of capturing subjective perceptions (17, 119).

The final method that is discussed here takes the concept of capturing individual perceptions a step further. Instead of pre-determining the domains and items that make up QoL, individuals choose the domains and items important to them, indicate their satisfaction with these domains and items, and finally decide the importance of these domains and items relative to one another (17, 113, 119). This method is used in highly individualized QoL measures such as the Patient Generated Index (PGI), the Measure Yourself Medical Outcome Profile (MYMOP) and the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (17, 119-122).

With the current study data, it is not possible to say which of the aforementioned methods is the best way of capturing subjective perceptions in critical care survivors. However, two points of consideration indicate that some methods may be more suitable than others. First, the critical care population tends to be extremely frail in the initial period of their recovery, and thus, respondent burden is a very important consideration, particularly when there are plans to measure survivors' HRQoL soon after hospital discharge. Capturing subjective perceptions using methods such as direct valuation of health states, additional questions and highly individualized measures can significantly add to respondent burden (13, 17, 119). Therefore careful deliberation is needed before employing any of these methods in survivors, especially at the beginning of their recovery.

Second, the possible use(s) of the results, obtained by the various methods, also need to be taken into account. For instance, although highly individualized measures appear to capture subjective perceptions in the most complete way, the scores obtained from such measures are arguably not suitable for use in studies involving the evaluation of health care interventions in a population of survivors (13). This is because scores for individual survivors are generally based on different domains and items and thus, they are not truly comparable (13, 17).

These points of consideration help focus the deliberation over which methods would work when it comes to capturing subjective perceptions in survivors. However,

more work has to be done to establish the best way forward concerning how to resolve the existing conflict between representativeness and relevance when using (standardised) measures to capture survivors' HRQoL. If it were decided that it would be desirable for the specific measure to capture survivors' perceptions, the various methods would need to be field tested in survivors, to determine which one of them strikes the best balance between capturing their perceptions thoroughly and respondent burden.

9.3.2. Level of detail and specification

The level of detail and specification (to be) used in the specific measure is another key consideration. From the study data, it is difficult to ascertain what level of detail and specification is optimal for the questions and response choices of a specific measure used in the assessment of survivors' HRQoL. Both general and specific content have their own advantages and disadvantages.

On the one hand, it makes sense to keep the content general in nature. The critical care population is very heterogeneous; they suffer from many different problems, with varying consequences for their daily life. By keeping the content general, far fewer questions and answer choices would be needed to capture what is important and relevant for survivors. This, in turn, would keep respondent burden to the minimum possible. As already stated, many survivors tend to be very frail for a significant period of time after hospital discharge and thus, respondent burden is a particularly important consideration to keep in mind.

On the other hand, content with a low level of detail and specification has its own pitfalls. First, non-specific content may leave respondents feeling that their true state is not being reflected, as revealed by data from this study. Survivors such as participants 08 and 19 said that whilst they could place their responses to the questions within the choices given, they felt that inadequate information about their lives was being conveyed. As participant 08 said about the EQ-5D, "...it's quite general, it's not very specific...mainly the problem I have in walking about is on uneven surfaces...I can walk for a certain length of time on the flat but if it's uneven surfaces I'm terrible."

Second, when the content is not precise, it is open to individual interpretation. For instance, the study data have shown that certain questions, like those which included the term 'health' in the SF-36 or the term 'health state' in the EQ-5D, seemed to be particularly prone to individual interpretation, because the definition of health tended to vary from survivor to survivor. For participants 07 and 20, the term 'health

(state)' referred purely to physical health. In contrast, participants 01 and 23 had a more complicated definition of 'health (state)'; participant 01 interpreted it as both physical and emotional/psychological health, whereas participant 23 saw it as physical, emotional/psychological and cognitive health. There was also evidence showing that questions such as those seeking to capture respondents' activities associated with their societal roles in the SF-36 (Questions 4, 5 and 8, questions on what was termed 'role functioning' by the developers of the SF-36) were construed differently by survivors compared to how the developers intended. For example, participant 10 saw these questions as also asking about her leisure and recreational activities although the questions were not aimed at such activities. Clearly, how survivors interpret the question(s) affects the domains the questions cover. These domains may not match what the developers of the questionnaire originally intended, and also, the domains captured are inconsistent across survivors.

Third, non-specific content may give rise to some confusion with regard to exactly what is being asked. For example, when completing the SF-36 and EQ-5D, a number of survivors wanted to know whether they were meant to take their pain medication into account when answering the question on pain, as this would affect their answers. As participants 19 and 25 said, they would both definitely be in 'extreme' pain without pain medication whereas the pain medication would place their pain more in the 'moderate' category. Neither the question in the SF-36 nor that in the EQ-5D explicitly provide guidance in that respect, and the distinction was clearly important enough for survivors to clarify exactly what the question was asking.

Fourth, when content is general and require respondents to integrate information about many different aspects into a single valuation, this may be difficult for respondents. This struggle is especially likely to occur when there are significant differences between the various aspects to be integrated. For example, when participant 23 was asked to assess her health state on the visual analogue scale in the EQ-5D, she felt unable to do so because there was significant discrepancy between her physical status and her mental status (which for her, meant her emotional/psychological status and her cognitive status). She felt that if she tried to merge these different aspects of personal status, she would have failed to convey valuable information, and that the single valuation would not truly reflect her personal status.

Fifth, general content, by its very nature, has non-directive wording and this can sometimes act as a barrier to respondents providing valuable and relevant

information. For example, survivors such as participant 12 and 16 did not talk about significant cognitive changes until they were prompted using fairly specific wording. From their reactions, it was clear that they did not spontaneously talk about these changes because they had not made the connection between their illness and their cognitive changes, rather than because these changes were not significant to them. The more directive prompts helped uncover information that would otherwise have remained undiscovered. Such opportunities to obtain crucial information would be lost by general questions with the less specific wording.

Finally, there will be limited information about specific domains and sub-domains, which may be considered a disadvantage for the users of the questionnaire(s), depending on what information they are seeking. For instance, the visual analogue scale in the EQ-5D would capture cognitive status if the survivor filling in the questionnaire saw 'health state' as incorporating his/her cognitive status. However, this question, in asking individuals to integrate information about various aspects of their personal status into a single valuation, would not yield specific information on cognitive status even if it were captured. Therefore, if users of these questionnaires need such information for clinical or research purposes, they would have to obtain it through other means.

Conversely, a high degree of detail and specification in the content would result in the reverse of the situation described above. Respondents may feel that the questionnaire better reflects what is important and relevant to them in terms of their HRQoL. There is also less scope for confusion and individual interpretation, with more specific information available. In addition, there would be less need to integrate information about various different aspects, which would simplify the cognitive processes needed to answer the questions. Consequently, respondents are less likely to struggle when answering questions. Finally, the specificity of the content may help increase information collected, as already highlighted in the case of participants 12 and 16. Both of them only talked about their cognitive changes when specific prompts made them aware that these changes might be due to their illness. Specific questions can serve the same purpose.

The big disadvantage of having a high degree of detail and specification is that a significant number of questions would have to be asked in order to cover the diverse changes faced by survivors, and the impact these changes have on their daily lives. Such a questionnaire would impose a substantial burden on respondents. Given survivors' poor personal status after critical illness, this is undesirable and may be

considered unacceptable by many. The unacceptability can in turn increase missing data, which would compromise the integrity of any information collected using such questionnaires.

Therefore, it is obvious that there is a fine line to tread in terms of the optimal level of detail and specification in a specific measure for survivors. The discussion so far has highlighted that asking about the various aspects of an individual's personal status separately is worth considering. In addition, one can also argue that the impact of different aspects of survivors' personal status on the various areas and sub-areas of life should be assessed individually. Finally, it would be useful to ensure that the wording of the question(s) is specific enough for survivors to know exactly what they should take into account when answering the questions, particularly in relation to whether they should take environmental factors in consideration. Given that many survivors appear to be reliant on environmental factors in their daily lives, especially early on in their recovery, there is the potential for confusion among a significant proportion of survivors. Thus, minimizing the possibility of confusion should be attempted. In addition, by explicitly specifying whether environmental factors are involved or not will help achieve consistency across the individuals filling in the questionnaire. Even though this was not expressly explored with study participants, it is possible that they did not answer questions where such factors applied in a uniform manner. Some individuals would have included the effects of environmental factors when answering the questions, while others would not have taken these factors into account. This means that different data are being collected from different individuals, which is undesirable when such information is often sought for comparative purposes.

Given that survivors' physical, emotional/psychological and cognitive statuses are all affected, with the various aspects exerting far reaching effects in many areas of their lives, even doing/having just the above may yield a questionnaire too cumbersome for survivors. A more detailed assessment with field-testing is needed before it is clear where the best balance is for survivors. Regarding the wording for the measure, the desired level of specification is seen in the International Classification of Functioning, Disability and Health, and the document should be consulted when considering the wording of the specific measure. However, to know for certain what would work best for survivors, field-testing would again be required.

9.3.3. The measurement of temporal changes

The science of measuring temporal changes should also be given some additional thought. Evidence from the study has shown that when a change has

significant fluctuations over time, it can be difficult to truly reflect it with the condensed questions and response choices that are characteristic of standardised questionnaires. A good example of this is pain. In some survivors, their pain intensity varied from day to day and even hour to hour. Just because they were in extreme pain at a certain time on a particular day did not mean that they were in the same state through the day or like that every single day. This variation in pain intensity tends not to be captured by questionnaires as shown by recent studies (123). This fact is also supported by data collected in this study; survivors completing the EQ-5D explicitly pointed out that the question on pain (Question 4) did not capture the fluctuation of their pain effectively.

However, interestingly, none of the survivors filling in the SF-36 raised the same issue, possibly because the SF-36 asks about pain over four weeks as opposed to one day in the EQ-5D (the day respondents complete the form). The longer time period of four weeks may have allowed variations in pain intensity to be captured more effectively than the time period of one day. As such, survivors completing the SF-36 might have felt that any loss of information in summarizing their pain experience over four weeks was not significant, at least not enough for them to raise the problem. If that were the case, there is some rationale in assessing any fluctuating problem over a more significant period of time. It should, however, be borne in mind that involving recall in such assessments may skew results (124).

Besides capturing fluctuating changes over a longer period of time, another suggested way of capturing such changes, made by participant 19, was to ask specifically about peaks and troughs of the changes. She felt that if she were asked to define her good days and bad days, the variation would be reflected more effectively. Therefore, this is another strategy worth considering when it comes to capturing changes that are temporal in nature.

9.3.4. The elicitation of sensitive information

The final point of deliberation when it comes to a critical care-specific measure is how best to elicit information about sensitive topics from survivors. The study data have indicated that a number of changes experienced by survivors are perceived as personal and private and/or have the capacity to adversely affect how survivors appear to others (essentially such changes are what Tourangeau et al. refer to as 'socially undesirable' (125, 126)). Changes possessing (either of) these two qualities essentially constitute sensitive topics (126). For participants of this study, such changes tended to be related to their emotional/psychological status and cognitive status

(rather than their physical status).

When changes are viewed as sensitive topics, survivors may be less forthcoming with information (126); they may misreport these changes, refuse to answer the whole questionnaire (unit non-response), or decline to answer the questions on these changes (item non-response) (17, 126).

These concerns about survivors being less open with information are supported by interview data collected during the study. As participant 24 said, even though she had very frequent nightmares, she would not indicate this on a questionnaire even if she were asked directly. This was because she deemed such information too personal to share on a questionnaire.

Similarly, participant 25 was reluctant to share accurate information about some of the changes that had occurred after critical illness. After completing the EQ-5D, she articulated that she had misreported her responses to some of the questions asked and did not choose answers which would have been a more accurate reflection of what she was like. The answers she did not choose but which would have captured her personal status and life more accurately were all answers that would indicate a worse state. For example, when debriefing about the questionnaire during the 'questerview', she said that she felt unable to do her usual activities, but in the questionnaire, she answered 'I have some problems with performing my usual activities' as opposed to 'I am unable to perform my usual activities' and this was a recurrent theme for her for most of the questions asked. When asked why she did that, she said, "You just don't like to admit fault really.". The fact that she was reluctant for others to know that she had been very badly affected by her critical illness was quite obvious throughout the interview. She kept talking about strategies she employed to maintain a facade of normality. For instance, she said, "And memory things, I've made constant adjustments for and learned avoidance strategies and all sorts at work...Like if somebody asks me something on the hop that I should be able to recall, I always go, "I'm desperate for the loo, can I get back to you in a minute?" and go away and have a little think. And just, there's some students in and we're supposed to be writing a final assessment for them, and I just assumed that the tutor would give us the forms to take away to fill out. She wants it doing on the spot. I can't do it on the spot. I can't recall. But I can't say to her, "I can't actually recall." So I said, "I'm really sorry. I've got a lunchtime appointment at the doctor's."...I said, "I'll have to email you it tomorrow." Just all those things to stop yourself looking incompetent and stupid.". Such urges to cover up the changes that have occurred after critical illness were also

shared by other study participants such as participants 11 and 23.

From such data, it is evident that for some survivors, many of the changes after critical illness were personally viewed as undesirable changes. This is most likely because there is often strong stigma (public as well as self stigma) attached to these changes, and especially, to the emotional/psychological and cognitive changes (127-130). Such stigma means that affected individuals are often “reduced....from a whole and usual person to a tainted, discounted one” (131). For instance, participant 23 associated her cognitive decline with being “damaged”, as seen in this excerpt, “People might be seeing you as slower and you don’t want people to think that you’re damaged, even though the professor said I am.”. Consequently, survivors were ashamed of these changes and seemed less inclined to share information about them. This reluctance to share information would render it difficult to capture some changes and compromise the measurement of survivors’ HRQoL. It is, therefore, vital to look for ways to encourage survivors to share relevant information, including that on sensitive topics.

Starting from the study data, there is evidence to show that survivors will provide the relevant information when the conditions are sufficiently encouraging, such as when there is a relatively prolonged encounter during which adequate rapport can be built. For instance, participant 13 spontaneously pointed out that sexual activity should be assessed when looking at HRQoL of survivors. This particular aspect of life is arguably even more sensitive to discuss on a questionnaire or with a stranger when compared to problems like nightmares or poor cognitive status. It may be that this survivor was less inhibited in that respect, but there is a strong possibility that it is because he had spent a significant period of time with me by then (at least four hours), and had established enough rapport to be so open. This latter reasoning is supported by the fact that participant 24 had also commented that the information she gave me had been given because of the time spent with her. Therefore, although some of the changes after critical illness are considered sensitive areas by survivors, the data show that the changes can still be captured accurately if circumstances are conducive.

On the other hand, it may be impossible, within the context of administering a questionnaire, to build rapport to the extent that survivors are comfortable sharing information on sensitive topics. Most study participants had spent at least an hour with me during their in-depth qualitative interviews, which gave ample time for establishing significant rapport. Administering a questionnaire usually takes a far shorter length of time, which would lessen the chances of building the kind of rapport

required for survivors to share sensitive information.

Unfortunately, with the available study data, it is only possible to conclude that when interviewers are used, adequate rapport with study participants may help make even information on sensitive topics available. This is not so much to do with the questionnaire content, as it is to do with how the questionnaire is administered. The study lack information on how the content of questionnaires can encourage survivors to share sensitive information, because finding out about how to help survivors be more comfortable with sharing sensitive information on questionnaires had not been a focus of the study.

However, the need to obtain accurate information on sensitive topics is not a novel concept and there is appreciable knowledge with regard to the collection of sensitive data in questionnaires. The current knowledge base supports the fact that individuals avoid giving accurate information on sensitive areas because they want to avoid the adverse consequences (such as embarrassment) that can occur alongside the disclosure (17, 126, 132). Unsurprisingly, therefore, the strategies that will help individuals avoid the consequences they want to avoid or increase the motivation for them to be honest (or both) can reduce non-response and facilitate the elicitation of more accurate information (17, 126). Some suggested and/or tried methods pertaining to the content of questionnaires include:

1. Formulating questions so that their answers can be used by specialised techniques to estimate answers to sensitive questions (126). Investigators have developed a variety of ways that will enable them to gauge the answers to sensitive questions from other data provided by individuals under study (126).
2. Manipulating the question wording such that there is a favourable platform for honest answers (126). For instance, if the wording of a question suggests that a certain experience or behaviour pattern will come as no surprise to others, individuals would be less likely to conceal that experience or behaviour (126). Using common terms can also help (126).
3. Asking sensitive questions later in the questionnaire (17).
4. Indicating that the sensitive questions are noncompulsory in questionnaires (17). This will only help in unit non-response (17).

Not every aforementioned strategy will be suitable for the purpose of eliciting information to capture survivors' HRQoL. The methods that are unlikely to work well are: using specialized means to estimate survivors' answers to sensitive questions and letting survivors choose whether to answer the questions. With these two strategies,

the assessment of survivors' HRQoL could be less accurate.

With respect to the other two methods, they may be effective strategies that will help ensure that survivors provide the appropriate information required to indicate their HRQoL. To definitively establish whether these strategies would work in the critical care population, more exploratory work would need to be carried out by using the strategies with survivors themselves. In addition, research needs to be carried out on the finer details like the exact kind of wording that will help most survivors to open up and give the relevant information.

Given that a number of study participants had indicated that they would withhold crucial information when it came to sensitive areas, research in this area should be conducted during the course of selecting or developing a specific measure for survivors. This is because, if there is inadequate knowledge on how to capture information on sensitive topics with questionnaires, survivors' HRQoL would not be wholly captured (133) and assessment of this important outcome would be compromised. It is, therefore, vital to know which strategies would work when it comes to using questionnaires to elicit sensitive information from survivors.

9.4. Conclusion

Besides helping to identify the domains and sub-domains to be included in a specific measure for survivors, the study data also pinpointed some of the other areas that are pertinent to the content of the specific measure. These areas include:

- The importance of capturing survivors' perceptions.
- The appropriate level of specification and detail for a measure to be effective for survivors.
- The measurement of fluctuating changes.
- The elicitation of sensitive information.

Having explored these other areas that have implications for the content of a critical care-specific measure, the review of all study findings pertaining to the content of such a measure is now complete. To conclude, the next and final chapter makes recommendations on the content of a specific measure for survivors in light of these study findings. It also discusses the strengths and weaknesses of the study, considers the contribution of the study to the field of HRQoL measurement in critical care survivors and provides some suggestions for future research.

Chapter 10: Conclusion and recommendations

10.1. Introduction

The main aims of the study were:

1. To explore what constitute HRQoL from the perspective of adult, general critical care survivors.
2. To ascertain the extent to which the current expert consensus generic measures capture survivors' HRQoL.

This imparted an understanding of the appropriate content for a specific HRQoL measure for critical care survivors, including insights into how the content of the specific measure could best complement that of the current expert consensus generic measures for this population-the SF-36 and EQ-5D. Such knowledge is vital given that a critical care-specific measure that helps capture the full impact of critical illness on survivors' QoL will be an invaluable tool for the evaluation of healthcare interventions targeted at improving patient-centred outcomes of critical care survivors.

Based on the findings from the study, this final chapter makes recommendations on what is required in a critical care-specific measure. This is followed by a discussion of the strengths and weaknesses of the study methods and data, and an assessment of the contribution of the study to the field. The chapter then concludes with some recommendations for future research.

10.2. Recommended requirements for a critical care-specific measure

10.2.1. Domains and sub-domains that should be covered

A. Survivors' personal status

Regarding survivors' personal status, the domains that need to be assessed more comprehensively in the specific measure are emotional/psychological status and cognitive status.

Fully capturing these two conceptual domains can be challenging. Naturally, with the heterogeneity of the critical care population, the specific reasons for each survivor's emotional/psychological and cognitive statuses tend to differ widely. For example, profound anxiety may be responsible for a particular survivor's poor emotional/psychological status while confidence problems may be the reason in another. Therefore, assessing survivors' emotional/psychological or cognitive status by going through every change that could possibly arise will place a tremendous burden on these survivors and may well be infeasible, despite a particular survivor, participant 11, expressing an opinion to the contrary.

Thus, if survivors' emotional/psychological and cognitive statuses were to be

directly assessed, an overview should be obtained, rather than asking about specific changes in their emotional/psychological or cognitive statuses. Examples of specific problems would be anxiety (emotional/psychological status), or memory problems (cognitive status). Obtaining an overview will keep the number of questions needed to cover these two conceptual domains to a minimum, thereby avoiding imposing too heavy a burden on the survivors.

Another possible way forward is to indirectly assess these aspects of survivors' personal status through the impact they exert. This is supported by the fact that when survivors talked about various changes in their personal status, often as not, they spoke about them in terms of how these changes had affected their lives. For instance, when participant 12 spoke about her lack of concentration, she described how it affected her reading and interfered with her watching the television.

However, describing changes in personal status in terms of their impact is probably more relevant to the cognitive aspect of survivors' personal status. Emotional/psychological changes can affect QoL simply by how they make survivors feel. Therefore, while the cognitive aspect of a survivor's personal status can be reasonably assessed via their impact, survivors' emotional/psychological status may still have to be assessed directly.

B. Impact of survivors' personal status

In terms of the impact of survivors' personal status, the domains and sub-domains that need to be included are⁶⁶:

- Some of the restrictive effects exerted by physical status and emotional/psychological status on activities and behaviours.
- Increases in activities and behaviours caused by physical status and emotional/psychological status.
- Impact of cognitive status on activities and behaviours (both restrictive effects and increases in activities and behaviours).
- Impact of personal status on:
 - Perception of, interpretation of, and responses to life.
 - Personality.
 - External appearance.

⁶⁶ Emotional/psychological consequences and cognitive consequences would be captured if survivors' emotional/psychological status and cognitive status were adequately assessed, as per the earlier recommendations. Thus, they have not been included in the list as domains and sub-domains to be covered in the specific measure when assessing the impact of survivors' personal status.

- Physical zone of comfort and/or activity.
- Suitability and availability of clothes.
- Interactions and relationships with others.
- Place of residence.
- Finances.

For more specific details on the exact effects to include, please refer to the relevant chapters in the thesis.

10.2.2. Other recommended requirements (See Chapter 9 for more details)

To further refine the measurement of survivors' HRQoL, the specific measure should incorporate the following:

- Specifically capturing survivors' perceptions of their personal status and the impact this has on their lives.
- General questions to minimise respondent burden. However, ideally, the various aspects of an individual's personal status should be assessed separately. In addition, there is also an argument for assessing the impact of different aspects of survivors' personal status on the various areas and sub-areas of life individually. Finally, the wording of the question(s) should be explicit enough for survivors to know that they should take environmental factors into consideration when answering the questions.
- Changes that are known to fluctuate over time should be captured over a longer period of time. Alternatively, an assessment of their peaks and troughs can be made.
- Strategies that would encourage survivors to provide accurate information within the questionnaire. Examples of such strategies include wording the question such that it promotes honest answers and asking sensitive questions later in the questionnaire (17, 126).

10.3. Strengths and limitations of study

10.3.1. Strengths of study

A. Strengths of study design and implementation

Every effort was made during study design and implementation to ensure that survivors' views were systematically collected and analysed, so that the resultant conceptual framework would be as robust and as symbolically representative of the entire critical care population as possible. In addition, the study was designed to explore, in some detail, survivors' cognitive processes when completing questionnaires. These maximized the validity of the findings with regard to:

1. The extent to which the current expert consensus generic measures for this population capture their HRQoL.
2. The recommendations made with regard to a critical care-specific measure.

These strengths are discussed in turn in this subsection.

I. Strength of sampling strategy

A combination approach to purposive sampling based on both the principle of maximum variation sampling and the principle underlying theoretical sampling⁶⁷ was used. In essence, characteristics that were likely to affect how survivors define their HRQoL were used to select and recruit participants such that maximum variation within the selection criteria occurred among these participants. The characteristics (age, sex, ethnicity, admission diagnoses and lengths of stay) that were initially used to select participants were identified using knowledge gleaned from the literature review and the interviews conducted by the Health Experiences Research Group. In addition, a decision was also undertaken to recruit participants who were between six and twelve months after discharge from critical care, to allow for recovery time without overly compromising information recall. These characteristics were later reviewed using findings from an initial analysis of ten interviews, along with some consideration to the practicalities of recruitment. The initial analysis did not highlight the need to change any of the initial selection criteria, but the practicalities involved in the recruitment of participants and in the arrangement of interviews dictated three main changes. These were: (i) only British White survivors were included; (ii) only emergency admissions were studied; and (iii) participants had to be between six and fifteen months after discharge from critical care.

Sampling and recruitment of participants continued until there were no obvious new themes emerging from the data (the point of 'data saturation'). For this study, the point of 'data saturation' occurred after twenty-five study participants had been interviewed. Such a sampling and recruiting strategy was adopted so that even disparate views of the concept of HRQoL would be obtained, which would, in turn, increase the applicability of the framework within the critical care population.

II. Non coercive recruitment process

Every effort was made to ensure that participants did not feel coerced to take part in the study:

- None of the participants recruited were ever under the direct care of the

⁶⁷ For a more in-depth discussion of the sampling method, please refer to Chapter 3.

researcher.

- Participants were given at least 24 hours to consider whether they wanted to take part in the study.
- They were reassured repeatedly that not taking part in the study would not affect their medical care in any way
- They were asked more than once whether they were definitely happy to take part.

This was to optimize the likelihood of participants expressing their views candidly and in depth.

III. Optimization of data collection method

The interviews were organized and conducted such that high quality data could be obtained and the goals of this study satisfactorily fulfilled. First, for all the interviews conducted for this study, the in-depth interview based on the topic guide was always carried out before the 'questerview'. This helped ensure that participants were able to speak freely about what truly mattered to them with minimal interference from the content of the two questionnaires. If the two HRQoL measures had been introduced at an early stage, there would always have been the possibility that participants ended up having preconceptions about what kind of data was being looked for rather than using their own discretion. Introducing the HRQoL measures only after participants had spoken about what they felt was most important to their HRQoL minimised the possibility of data interference by these outside influences and increased the validity of the study findings.

Second, during the 'questerview', survivors were urged to share the cognitive strategies they employed when answering the questionnaires, in particular, any difficulties they faced. This yielded insight into the (other) problems that could arise from the content of (standardised) questionnaires when questionnaires were being used to capture survivors' HRQoL.

Third, as with the recruitment process, there were a number of steps taken during the interview process that were geared primarily at getting survivors to be open. One of the strategies was to help participants feel that they were in control. Participants were all interviewed in their own homes and were given considerable say in the circumstances surrounding the interview. For instance, if a participant wanted to have a relative stay in the room while the interview was taking place, it was not insisted that the relative leave the room. Care was also taken to ensure that the survivors were the ones to set the pace and length of the interview. It was reiterated to

them that they were free to take a break at any time or ask for the interview to be finished on another day. I also checked periodically throughout the interview that participants were happy to continue. All this was done to help participants feel comfortable and in control of the situation.

In addition, before starting the interview, time was spent building rapport and putting participants at ease as well as emphasising to them that their uncensored views would be most conducive to the study. In particular, they were specifically told that they should not just speak about what they thought would be of interest to me, but rather to discuss what was important to them when it came to their HRQoL after critical illness.

Finally, I tried to minimise interference in the form of interruptions, steering or prompting.

All these steps seemed to be fairly effective. Many of the participants spoke at length and in great depth, with most interviews taking more than an hour to complete. In addition, the majority of participants appeared very open, with a number spontaneously mentioning sensitive topics such as sexual problems. A few of the participants even specified during their interviews that they were speaking of things that they had never spoken to anyone else about before. In fact, in the case of one participant (participant 22), his wife, who was present during the interview, attested to the fact that what she was hearing was completely new to her although she was very close to the participant and they had discussed the whole critical illness and recovery experience at length. This made for very rich data and provided considerable insight into what being a survivor of critical illness was like and what mattered to these survivors.

Besides encouraging participants to speak freely, some of the steps undertaken might also have had other positive contributions to data collection. Having a relative (that is an additional person) present, with input from him/her, served to further deepen insights into the critical illness and recovery experience (There were also disadvantages to having a relative present but these are discussed later, when the limitations of the study are being explored.). For instance, although participant 04 shared some of his worries during the first part of the interview when he was alone, it was not until his brother arrived that it became very evident that worry and anxiety were big problems for him on a day-to-day basis.

Allowing participants to set the pace of the interview was another one of the steps that improved data collection in other ways. Some participants requested that

the interviews be completed over two sessions, which had its advantages. It provided an opportunity for the data already collected to be reviewed so that further clarification could be sought as necessary.

Furthermore, the data collected during the second meeting often had greater depth for two reasons. A second encounter enabled a level of rapport and trust beyond what was possible with only one meeting, thus creating a secure environment for participants to cover territory they would not otherwise have covered. For instance, as already stated earlier, participant 22 apparently shared information that he had never spoken about to anyone previously; he revisited memories of the hallucinations he had had while in hospital and described them in some detail. Although he had fleetingly brought up the fact that he had hallucinations and nightmares during the first encounter, it was only during the second meeting that he went on to describe these hallucinations and nightmares in any kind of detail. It was likely that it was only during the second meeting that he felt safe enough to delve into memories that were clearly very painful for him. Admittedly, he said that he had chosen to speak about these memories because he wanted to help others with the information. However, a certain level of trust and rapport must have been present for him to share something that he had tended to block out because of the painful emotions it invoked in him. Having a second meeting most probably helped with that.

Finally, there was also some evidence that the first meeting often provoked participants to consider their experiences more thoroughly, which could add depth to the data collected during the second encounter. Participant 12 said expressly at the end of the first encounter that she felt that she had a clearer idea of what the study was trying to uncover. She was going to try and recall everything she felt relevant to the study before the second encounter, which would have helped obtain better/fuller data at the second meeting. The postulate that data collection would be facilitated by having time to contemplate the study has some definitive support. First, it is substantiated by some empirical data from the study. Some participants only recalled important information after the interviews; one participant texted with what he felt was relevant information that he had forgotten to mention, while another (who gave permission to be re-contacted after the interview) gave further information when she was telephoned for further clarification of (unrelated) data. Second, it is also in line with some current research findings (132).

IV. Triangulation of data collection strategies

The study used triangulation of methods to improve the validity of the findings;

two strategies of data collection were used to obtain information about what constituted HRQoL among survivors. They were encouraged, in the first part of the qualitative interview, to speak freely about how critical illness affected them and their lives. In the second part of the interview-the 'questerview'-the current expert consensus generic measures for them were then used as a basis for exploring the same topic. This included asking them to identify the gaps in the measures, which helped clarify what really mattered to them and thus, was likely to influence their QoL.

In addition, two methods were used to ascertain the extent to which the current expert consensus generic measures for the critical care population-the SF-36 and EQ-5D-captured survivors' HRQoL. First, the content of the questionnaire was compared with the data collected from the qualitative interviews, to evaluate how well these questionnaires captured the revised conceptual framework for survivors' HRQoL. Second, the study participants were asked for their opinions on whether these measures adequately captured their HRQoL, and also to identify any perceived gaps in the instruments.

It must, however, be said that the strategy of asking survivors to identify gaps in the instruments was not particularly effective (this is discussed further when limitations of the study are being explored), thus restricting, to some degree, the extent to which data could be 'triangulated'.

V. Strategies to preserve the integrity of the data analysis

During the course of analysis, care was exercised to ensure, as far as possible, that survivors' views were preserved and not mis-represented. An open mind was kept about what would arise from the data and ideas about how the data should be coded were kept fairly fluid in the initial stages. This was so that emerging patterns would not be missed or forced to fit into a rigid, preconceived framework too early on. Codes were derived, as much as possible, from the words that participants had used.

Furthermore, given that the risk of mis-representation was highest when analysis was carried out in isolation (134), codes, especially initial ones with related transcripts, were discussed with my PhD supervisor and a critical care survivor who was also doing qualitative research. This was to prevent me, a medical doctor, from medicalising what the participants were saying.

Last but not least, during the course of the analysis, a continual assessment was carried out on whether the same findings and conclusions were reached from data obtained using two different methods. As already stated, participants were first asked to talk about the impact of critical illness with me refraining from interrupting or

steering them as much as possible. This topic was then explored again using the SF-36 and EQ-5D as the basis for discussion. The findings and conclusions drawn from these two methods of data collection were continually checked against each other.

Similarly, two strategies were used to determine the extent to which the SF-36 and EQ-5D captured survivors' HRQoL. The content of the questionnaires was compared to the data collected during the qualitative interviews. Survivors were also asked directly whether the measures captured their HRQoL and whether there were any gaps in the measures. Again, findings and conclusions extracted from the two data collection strategies were constantly compared against each other.

B. Strengths injected by individuals involved in the study

Besides deliberate design and implementation decisions contributing to the validity of the study findings, the individuals involved in the study also played a part in the study gleaning exceptional insights into how critical illness affects survivors' HRQoL, which in turn increased the robustness of the conceptual framework for survivors' HRQoL.

I. Recruitment of less accessible participants

The two clinicians responsible for the identification and recruitment of participants enjoyed excellent relationships with the potential participants because they were already following up (the majority of) this particular group after their critical illness. Therefore, they were in a strong position to provide support for the study; they were able to follow up with the participants to ensure that any distress provoked by the study interviews would be dealt with.

It was fortunate for the study that both clinicians were happy to provide this support for most of the study participants although for those not already well known to them, the general practitioner was still the first point of referral for this type of follow-up care.

Although, as far as is known, no individual required follow-up support consequent to the study interviews, the clinicians' readiness to provide support still played an important role in the recruitment of study participants, as there were study participants who ended up participating only because they felt secure enough with the support procedures in place. A very good example was participant 11. Although she was keen to share her experiences and views so that these could be used to help others, recounting these was very painful and distressing for her. To protect her, a special arrangement with the clinician who recruited her (and who was already following her up) was put in place. It was agreed that the study interview would only

take place when the clinician was available by telephone from the time the interview commenced and when she could physically check up on the participant within 24 hours of the study interview. Although such arrangements required more coordination for all involved, they created a safer environment where risk of harm to participants was reduced and participants were assured of a significant amount of support should they become distressed. They helped recruit participants who would ordinarily have refused to take part in such a study for fear of not being able to cope. Having such participants involved, in turn, generated data that would otherwise have been inaccessible.

II. Different level of data collection and analysis because of researcher

I was a medical doctor with considerable experience with critical care patients. This helped in a number of ways. First, building rapport and getting a person to open up is integral to medical work, and this stood me in good stead when interacting with the study participants. Consequently, although it was made clear to all participants that I was there only as a researcher and that they should not treat the interview as a therapeutic encounter⁶⁸, a number of participants felt comfortable enough to reveal information that they had never discussed with anyone else before.

Second, the analysis was aided by the knowledge that I had as a critical care doctor. Whilst participants' interview data provided invaluable insights, they were not expected to precisely identify the nature of the change(s) they had been/were experiencing. For instance, when participant 10 spoke about getting distracted while going about a specific task, she described it in terms of a memory problem. Similarly, when participant 13 spoke about not being able to multi-task without losing track of what he was doing, he talked about it in relation to memory and concentration. With the knowledge that I had about possible cognitive deficits after critical care, the possibility that they might be describing problems with another cognitive sub-domain, specifically that of executive function, was kept in mind. This was later confirmed by the interview data from participant 17. She spoke about difficulty in problem solving and decision making, which clearly indicated problems with executive function. Accurately classifying the changes that survivors experience is important when it comes to delineating the domains (and sub-domains) of survivors' HRQoL precisely, and the ability to do so was aided by my knowledge.

⁶⁸ If participants viewed the interview as a therapeutic encounter, there was the danger that they would reveal more information thinking that help would become available to them 134.

Richards HM, Schwartz LJ. Ethics of qualitative research: are there special issues for health services research? *Family Practice*. 2002 Apr;19(2):135-9.

There is, of course, a disadvantage to this kind of knowledge, which is that participants' views may be mis-represented and analysed through a prior set of clinical lenses. To counteract this, participants were always encouraged to provide a full description of the changes they were experiencing in cases of ambiguity. Whenever anything appeared unclear, clarification was sought. The descriptions of the changes were then checked against the current knowledge base in the literature. Similar accounts were sought in the research and lay literature, so as to gain insights into their possible classifications.

Furthermore, whenever possible, an alternative code (and way of classification) that was different to the terms used by study participants to describe a phenomenon would only be created after checks were done to see whether there was additional corroborative data from other interviews. This was what was done in the case above relating to executive function. It was only when participant 17 described changes that firmly indicated that executive dysfunction was occurring that the additional code of executive dysfunction was created.

III. Enhanced data analysis because of study participants

Some of the study participants had great understanding and knowledge of the changes they had been/were experiencing consequent to their illness, which contributed significantly to data analysis. For instance, as already described, participant 17's interview data helped confirm that the additional code 'executive dysfunction' should be created. In her case, her previous profession (she was retired) meant that she had some specialist knowledge into cognitive changes. This gave her the ability to describe her cognitive changes in fairly technical terms, which made it easier to see that executive dysfunction was being reported.

10.3.2. Limitations of study

Although the study has numerous strengths that contribute to the robustness of the study findings, there are also limitations that may have compromised the findings and limited their applicability.

A. Limitations of study design and implementation

I. Restricted access and potential limitation of data applicability due to study sites and recruitment procedures

The study sites through which participants were recruited and the way participants were recruited meant that certain groups of critical care survivors were not readily accessible. In terms of how the study sites limited recruitment of certain groups of survivors, both study sites served populations who were predominantly

white. It naturally followed that most of the critical care patients seen at these sites were white and thus, recruiting survivors who were of other ethnic backgrounds was much harder.

With respect to recruitment procedures restricting access to particular groups of survivors, all participants were recruited via clinicians who were delivering critical care follow-up services in clinics (since this tend to be the only consistent contact survivors have with units after discharge) and therefore, some groups of survivors were more difficult to reach. The general policy of both clinics was to only invite survivors who had had a length of stay of five days or more⁶⁹ although the clinic at one of the study sites did invite survivors with shorter lengths of stay when they were not being followed up by any other specialty. This policy, alongside the fact that survivors with shorter lengths of stay were less prone to problems (96, 97) and thus, less inclined to attend clinic even when invited, meant that survivors with short stays (less than five days) were virtually impossible to recruit. As the vast majority of survivors who had been electively admitted tend to have short stays (135), this meant that electively admitted survivors were extremely difficult to recruit too.

Given the situation, it was decided that only White British survivors and survivors who had been admitted to the critical care unit as emergencies would be studied. As for the remaining group of survivors who were difficult to recruit (namely those with short stays but were not electively admitted), every attempt was made to recruit them. Despite these efforts, all the study participants had been in the critical care unit for at least three days. Consequently, survivors who are elective admissions to critical care, survivors who have stayed in the critical care unit for less than three days and survivors of other ethnic backgrounds (other than White British) are not represented in the study sample. This means that the impact critical illness has on such survivors has not been directly documented by the study.

Nonetheless, a certain degree of insight is still available, especially where the former two groups of survivors are concerned. Current research evidence suggests that many of these survivors tended to experience fewer and lesser effects from the critical illness episode (hence the policy by the critical care follow-up clinic) (92-97). If

⁶⁹ This policy is undertaken because survivors with shorter lengths of stay generally tend to have far fewer problems 96. Jones C, Backman C, Capuzzo M, Flaatten H, Rylander C, Griffiths RD. Precipitants of post-traumatic stress disorder following intensive care: a hypothesis generating study of diversity in care. *Intensive Care Medicine*. 2007 Jun;33(6):978-85, 97. Jones C, Griffiths RD. Identifying post intensive care patients who may need physical rehabilitation. *Clinical Intensive Care*. 2000;11:35-8.

anything, some of these survivors, particularly those who were planned admissions, were arguably better off than they had been before their admission to the critical care unit (92). Given that the conceptual framework does describe less severe changes and some positive changes, it would be at least partially applicable to short stay survivors and survivors who had been elective admissions to the critical care unit. However, because there may still be changes pertinent to short stay and electively admitted survivors that are not as well documented within the conceptual framework, the fact that the framework may be less applicable to these survivors and less able to discriminate between them must still be borne in mind.

As for the last group of survivors-survivors who are not White British, the current knowledge base indicate that because of cultural differences, survivors of these other ethnic backgrounds may define the concept of HRQoL differently from survivors who are White British (136-138). For instance, in a study conducted by Ashing-Gwa et al., there was evidence to suggest that outlook in terms of spiritual beliefs and God featured more strongly in the concept of HRQoL for African-, Latina-, and Asian-Americans compared to Euro-Americans (136, 139). Thus, to be safe, it should be assumed, until further exploratory work is done, that the conceptual framework built in this study is of limited applicability to survivors who are not White British.

II. Possibility of biased data consequent to limitations of sampling and recruitment strategy

As already mentioned, all participants involved in the study were sampled and recruited through two critical care follow-up clinics. Such a sampling and recruitment strategy may have introduced bias into the interview data collected, because there may be crucial differences between survivors who are actively being monitored through such services and those who are not (140), with such differences significantly affecting the data provided.

Fortunately, during the time when the study was sampling and recruiting participants, one of the critical care follow-up clinics responsible for participant recruitment was also reviewing critical care survivors who were involved in another study. Many of these survivors were not being actively followed up by the service; rather, they were invited back to the clinic to complete the processes required for the other study. Some of these survivors kindly consented to participate in this study and thus, opportunistically, the study sample did not consist solely of survivors who were being closely monitored by critical care follow-up services. In fact, during participant

23's interview, it became clear that she would benefit from being assessed by the critical care follow-up services but had not received such care⁷⁰. Having such survivors involved in the study would have offset some of the potential biases introduced into the data by sampling and recruiting entirely from a population who were/had been attendees at a critical care follow-up clinic.

III. Reduced data applicability imposed by nature of qualitative interviews

The study utilised qualitative interviews as its primary method of data collection and the nature of such interviews may have selected out certain types of participants.

Of all the survivors who consented to being contacted, one survivor declined to take part after having time to consider while another felt that she was not ready to be interviewed at the time she was contacted but was willing to be contacted at a later date. The former survivor cited the reason for declining as not being able to make time to do the interview. This was because she had returned completely to what she was like before her critical illness and was back at work. In contrast, the latter survivor was willing to take part, but was too traumatised by the whole experience to talk about it at the time of contact. She was awaiting therapy to help her come to terms with the experience and wanted to have completed that before taking part in the study and revisiting her memories. She therefore asked to be re-contacted at a later date. As the study had managed to recruit and interview all the required participants before the date she asked to be re-contacted, she was not approached again. From these two cases, it would seem that, on the one hand, if survivors have returned to their daily lives, the time consuming nature of qualitative interviews might be a deterrent to their participation. On the other hand, if survivors are still early in their recovery and are not as well as they used to be, the probing nature of qualitative interviews, and possibly the time required to engage in them, might also deter survivors from taking part. It is, thus, a possibility that the study sample was limited to survivors who were more or less in the middle of the spectrum when it came to their personal status and the state of their lives after critical illness.

Unfortunately, there was no additional data available to confirm or refute the postulate that the information collected in this study comes from survivors who fall into the middle of the distribution where their personal status and their day-to-day living are concerned. As part of the research ethics approval for the study, the details

⁷⁰ After her interview, her details were forwarded, with her consent, to the clinician responsible for follow-up services in her area, and as far as is known, she has been followed up since.

of survivors who had been approached but refused straightway to participate were not released to me. There was, therefore, no way of ascertaining what kind of survivors would refuse to take part in such a study and whether there was a pattern that could be identified. Furthermore, the study did not endeavor to collect any information on why survivors refused to take part.

Consequently, to err on the side of caution, I assumed that the method of data collection has limited the applicability of the findings and that the conceptual framework would be most relevant for survivors who constitute the middle of the range in the critical care population.

IV. Potential data limitation due to interview procedures and content

The study design was such that most of the interviews conducted with survivors took place on a single occasion and involved them completing (i) a semi-structured interview based on a topic guide and (ii) a 'questerview', during which they were invited to complete either the SF-36 or the EQ-5D and provide feedback on the relevant HRQoL measure. Attempting to collect all the pertinent data during a single interview carried two undesirable consequences, both of which led to the ultimate (potential) outcome of limiting the data. First, as only a single interview was planned, survivors were asked to complete and review only one HRQoL measure (as opposed to completing both the SF-36 and EQ-5D). This was because survivors are often very frail and it was felt that asking them to complete both questionnaires after what could be a long semi-structured interview would cause unacceptable respondent burden. As a result, the amount of data collected on how critical care survivors perceived these measures was arguably not very substantial.

Second, there was a lot of ground to cover in a single interview, which could be/tiring for many of the survivors. Consequently, it was not inconceivable that data quality and depth was reduced due to respondent fatigue, especially in relation to the 'questerview' component of the interview. Given that the 'questerview' was a great opportunity for immense insights into how survivors perceive and assess HRQoL, the loss of quality and depth in the data collected during this component of the interview is particularly unfortunate.

If the study had incorporated two interviews, survivors could have been asked to complete both the SF-36 and EQ-5D, which would have effectively doubled the amount of comparable data collected in this study. Since the study only involved a small number of participants (twenty-five), it is imperative to maximise the corresponding data collected and thus, facilitate generalisability. Moreover, having

two separate interviews would have helped address the issue of respondent fatigue and in doing so, it may have increased the depth and quality of the data collected.

However, it must be said that survivors of critical illness are very frail and there was the genuine concern that planning for two scheduled interviews would affect recruitment. Having two separate interviews to complete might have discouraged survivors from taking part, especially those in a poorer condition. Not only would this make recruitment more difficult than it already was for this study, it would also have rendered the resultant findings less generalisable.

V. Possibility of data interference and mis-representation because of interview procedures

Although the way interviews were organized and conducted helped data collection, the interview procedures still suffered from flaws that might have limited data quality.

Data interference could have occurred from the presence of other people at the interview. To prevent damaging rapport, relatives wanting to stay for the interviews were allowed to, as long as the participants involved were comfortable with the arrangement and/or wanted them to stay. This was despite the initial study design specifying that participants were to be interviewed alone. Consequently, out of the twenty-five interviews conducted, three were conducted with a relative present⁷¹. Although the main reason for allowing these relatives to stay was to avoid making things awkward and thus jeopardizing data quality, the presence of an additional person might have compromised the data collected.

First, it might have restricted the participants and resulted in them not being as open with their account as they would otherwise have been. Although there was no strong evidence to indicate that this was the case with the three participants who had relatives present, it is nevertheless a possibility that needs to be kept in mind. For

⁷¹ Two of them were spouses. One was participant 03's husband and the other was participant 22's wife. It was most likely that participant 03's husband remained in the room where the interview was held because of space issues (as in there was nowhere else he could go to and comfortably stay in during the interview). As the interview was taking place in their home, an insistence that he went elsewhere might make things difficult and therefore, it was felt on balance that it was best not to ask him to do so. In addition, participant 03 appeared happy with the arrangement and did not display any signs of being reserved with her husband around. In the case of participant 22, his wife seemed to crave the social contact. Given that participant 22 constantly involved his wife while the study was being explained to him and appeared to be very close to her, it would seem that he was close enough to her to remain comfortable with her around and so, she was not asked to leave the room. The third interview with a relative present was in the case of participant 04. His brother turned up to visit in the middle of the interview and joined in. Again, participant 04 did not mind that he did that and even actively involved him in the interview.

instance, participant 12 (who was interviewed alone) brought up the fact that she spoke much more freely about what was troubling her when she attended her critical care follow-up appointments without her husband.

Second, having individuals other than the participant present might have reduced the subjectivity of the data. This would have gone against the goal of the study, which was to study HRQoL from survivors' own standpoint. The possibility that this could happen was seen in participant 03's case. She spoke about not being as tired and thus, not sleeping as much as when she had first come home from hospital. Her husband immediately interjected and said that she was still sleeping more than she had done before her critical illness. Although she agreed with him, she herself had not raised tiredness and sleeping more as significant changes that were still present at the time of the interview until her husband had said this. One could argue that she might have brought this up herself later on in the interview. However, the fact remained that while she might indeed be still more tired and sleeping more compared to before her critical illness (that is, objectively, there was a change), subjectively, the difference might not have been enough for her to see it as having a significant impact on her QoL. Unfortunately, this was not specifically clarified with her during her interview and it could not be definitively concluded whether or not she herself viewed these as important changes after her illness. Whatever the case, it is important to be aware that having someone else present during the interview might have caused some interference to the data collected.

Data interference could also have occurred because some participants had to be interviewed over two occasions. A combination of participants' frailty and the complexity of what they were going through (and had gone through) meant that some interviews could not be completed in one sitting. Participants 12, 13 and 22 all had to be interviewed twice. With interviews conducted on two separate sittings, participants would have had the opportunity to speak to others while pondering upon the study, thus interfering with the data collected. For instance, participant 12 definitely spoke to the people around her about the study in the period between the two meetings. She did say that they were not very willing to share their views and therefore, the influence exerted by others on the data she provided was likely to be fairly limited. Nonetheless, the potential of data influence was still kept in mind when her data were being analysed.

It must however be said that although there was a possibility that data interference could occur due to interviews being conducted on two occasions, there

was no real evidence that this had happened in this study. The three participants interviewed in two separate sessions did not say anything during their interview(s) that differed significantly from what had been said by participants who only had one interview.

Finally, there was some risk of data mis-representation because the interview procedures did not incorporate any mechanisms that would allow clarification on the interview data to be sought from participants. Although many participants specifically gave permission (without being asked) to be re-contacted at the end of their interviews should there be anything ambiguous or unclear about what they had said, there were no procedures in place or ethical approval for clarification to be sought on the interview data. While there were few instances when data needed to be clarified and could not be, it would have been better if authorised arrangements had been in place.

VI. Compromised triangulation of findings due to limited effectiveness of one data collection strategy

In the study, two strategies were used to collect data on: what constituted HRQoL among survivors; and whether the content of the SF-36 and EQ-5D captured survivors' HRQoL, so that findings could be triangulated.

For both these areas, one of the data collection strategies involved asking survivors for their opinion on whether the content of the SF-36 and EQ-5D accurately reflected their thoughts about their health and QoL, and whether the instruments failed to measure anything that mattered to them. Unfortunately, this data collection method did not seem to work very well in survivors. For instance, during the semi-structured part of the interview, participant 10 spoke extensively about how cognitive problems affected her. She brought up her problems without prompting and they appeared to have quite a significant impact on her life. Despite this, when it came to picking out the key areas of her life not included in the SF-36, she did not raise cognitive status and its effects as such areas. There were a few possible explanations for this including: (i) recovery to the extent that cognitive deficiencies and their effects were no longer problems; (ii) no real notable impact exerted by cognitive deficits; (iii) cognitive status and its effects did not contribute to her QoL; and (iv) the task of holding what mattered to her in her head, comparing it to what she thought the SF-36 was measuring and then identifying the gap was far too challenging. The last reason was the most likely. This was because the way participant 10 spoke about her cognitive problems and their effects implied that her cognitive status as well as the part it played in day to day living was quite relevant for her and her well being. This

probably held true for quite a number of survivors, which meant that this particular strategy would not have been particularly effective in obtaining the relevant information. Consequently, the degree of triangulation and cross checking of findings was more limited than originally planned.

B. Weaknesses introduced by the individuals involved in the study

I. Data collection and analysis compromised by relatively unseasoned researcher

I am relatively inexperienced in carrying out qualitative research and that may have had negative influences on data collection and analysis, especially given my medical background.

With regard to data collection, it was difficult for a novice in qualitative research to strike a good balance between allowing participants to speak freely and appropriately steering the discussion. Clarifying points with participants without shaping the data was difficult to achieve. This meant that the quality of the data obtained, especially at the beginning of the study, was likely to have been inferior to what would have been collected if a more experienced qualitative researcher had been conducting the study.

The same applies to qualitative data analysis; it is a skill that is difficult to develop rapidly. In addition, as a medical doctor, there was also the danger of pre-determining what was going on and thus, mis-interpreting the data.

To offset the inexperience as well as the potential biases, early interviews were read by my supervisor who was considerably more experienced in the field, and feedback was given. In addition, when analysing the data, guidance was sought from the supervisor and other more experienced researchers. Last but not least, I underwent formal courses in qualitative interviewing and analysis.

Although steps have been taken to minimize the impact exerted by the my inexperience and background, this still needs to be borne in mind, given that I was the main 'research tool' of the study.

In summary, the strengths of the study have enabled the collection of very rich data about the lives of survivors of critical illness. Consequently, this study has provided a very good understanding of the concept of HRQoL from the survivors' perspective. This is particularly true for White British survivors who have been moderately affected by their illness.

In contrast, the views of the following groups of survivors may not have been captured quite as well: survivors who are of other ethnic backgrounds (other than

White British); survivors who are minimally affected; and survivors who are extremely affected. Data interference may have also occurred, first, because others were present during some of the interviews and second, because some of the interviews were completed in two separate sessions. In addition, the quality of the data collected may have been compromised by my relative inexperience. Furthermore, although every effort was made to ensure that mis-interpretation of data and mis-representation of survivors' views did not occur, it is a possibility that cannot be entirely discounted. It was a complex topic, and as stated, I was a novice qualitative researcher and less able to take account of the biases of my medical background. Finally, triangulation and cross checking of the findings were compromised because one particular data collection strategy was too challenging for survivors and this had a negative impact on the data collected. This, in turn, limited the degree to which findings could be validated.

10.4. What the study adds to current knowledge

A. A conceptual framework for HRQoL built from the views of critical care survivors

As far as can be ascertained, there have been no published studies that have systematically sought the viewpoints of the adult, general critical care population (of any country/cultural background) and utilised these views to construct a detailed, patient-based conceptual framework for survivors' HRQoL.

Whilst there has been no lack of reporting on the many possible consequences that may befall survivors after critical illness, much of the literature has a different orientation. Some studies only include certain subsets of survivors (55, 141-143) while others focus their attention on some, and not all, of the consequences of critical illness (66-69, 72, 77, 79, 144-155). Even in studies that try to recount as many of the changes experienced by survivors as possible (38, 41, 42, 44, 45, 49, 52, 58, 59, 63, 64, 74, 156-159), it is unclear how important these changes were for survivors when it came to their HRQoL. There is also no way of knowing whether all the important constituents of survivors' HRQoL have been identified.

Furthermore, although there were two studies that had attempted to obtain survivors' perspective of the important influences over their HRQoL through qualitative interviews (53, 160), neither study sought survivors' views to the depth and extent that a precise conceptual framework for survivors' HRQoL could be built from these views. The Hall-Smith et al. study reported that physical, emotional/psychological and cognitive changes were experienced by survivors after

their critical illness and briefly commented on the fact that these changes in the various aspects of survivors' personal status affected their lives (53). With respect to the study by Brooks, the researcher extracted twenty-three categories that affected survivors' QoL from the qualitative interview data obtained (160). These categories, as reproduced from the document reporting the study (160), were:

- Health evaluation.
- Health effect.
- Past health.
- Health comparison.
- Acceptance health.
- Health precursor.
- Future health (hope).
- Medical intervention.
- Pain.
- Mobility.
- Self-care.
- Dependency.
- Employment.
- Finances.
- Activity loss.
- Emotional reaction.
- Adaptive behaviour.
- Self evaluation.
- Partner relationship.
- Change in responsibilities.
- Family relationship.
- Social relationship.
- Appearance.

In comparison to the findings reported in this study, the findings in the Hall-Smith et al. study were reported in much more general terms. The Hall-Smith et al. study focused only on providing a broad description of the physical, emotional/psychological and cognitive changes experienced by survivors after their critical illness, and did not provide many of the finer details. For instance, when describing survivors' physical status after critical illness, only weakness and fatigue were mentioned specifically. All other physical changes were classified under the

broad category of 'ongoing physical problems related to the illness' with no further details on what these physical changes were. The study also did not describe the consequences of survivors' physical, emotional/psychological and cognitive statuses in specific terms; it simply broadly documented that survivors' lives were affected by the physical, emotional/psychological and cognitive changes experienced by these survivors. In comparison, this study described the various aspects of survivors' personal status and their consequences in far greater detail.

As for the Brooks study, the findings were presented in more detail compared to the Hall-Smith et al. study. However, survivors' views of what constituted their HRQoL were still not delineated to the level of detail seen in this study. For instance, the study outlined that the category of 'mobility' influenced survivors' HRQoL but there was no detailed description on exactly how survivors' mobility was affected. Furthermore, it was impossible to judge whether these findings were plausible, as the interview data were not presented in any detail and it was, therefore, difficult to determine how the researcher derived the categories presented in the report. Finally, the report only gave a short example as a demonstration of what the categories encompassed and did not formally document the definitions for the various categories. Unfortunately, it was not always evident from the example given exactly what a particular category covered. Consequently, piecing together a full and accurate picture on what affected survivors' HRQoL from their perspective could not be achieved from the information reported in the study.

Besides not delineating survivors' views of the concept of HRQoL as precisely and in as much detail as that seen in the study conducted in this thesis, both studies also had significant methodological limitations. In both studies, convenience, rather than true purposive sampling, was carried out. In addition, there was no mention of whether data saturation was reached and therefore, there was no way of ascertaining whether everything that would have affected survivors' HRQoL was identified. Last but not least, in the study conducted by Brooks, there was the possibility that survivors' views had been influenced by a draft HRQoL questionnaire that was administered to them before their interview. As the questionnaire was developed using chiefly a top-down approach (where the content of the questionnaire was determined by a literature review with expert input but no input from the population being studied), it was unclear how much of the data obtained from the survivors interviewed truly represented their own views.

B. Ascertaining the extent to which the current expert consensus generic measures for this population capture survivors' HRQoL

Using the conceptual framework that was built upon the perspective of survivors, this study had definitively established the extent to which the SF-36 and EQ-5D captured the HRQoL of survivors. Although these two measures are the current expert consensus generic measures for this important outcome in survivors and many studies have utilised them, there appears to have been no research into the extent to which their content captures the HRQoL for this population. With this research, this particular knowledge gap has been filled.

C. Insights into some of the other important content-related considerations when using questionnaires to capture survivors' HRQoL

The study provided considerable insight into some of the other content-related issues that need to be considered when questionnaires are being used to capture HRQoL in this population. Although there has been some evidence indicating that using questionnaires to capture survivors' HRQoL can be problematic (161), there has been no formal research in this area. Despite the fact that this was not one of the main focuses of the study either, the study did explore, in some detail, the cognitive processes employed by survivors when they were completing the questionnaires. By doing this, it helped advance the knowledge in this area substantially.

Having reviewed the study's methods, its key findings as well as the contribution these findings make to current knowledge, the next section presents the implications of these findings for future research.

10.5. Recommendations for future research

The study has significantly contributed to the understanding of how critical care survivors view the concept of HRQoL. This understanding is particularly pertinent to White British survivors who have been at least moderately affected by the illness, but are still well enough to be fairly intensively interviewed. Knowing the aspects that are important to survivors' HRQoL has, in turn, helped establish the extent to which the SF-36 and EQ-5D capture survivors' HRQoL and enabled some initial recommendations to be made on the content of a critical care-specific measure.

However, to move the measurement of HRQoL in critical care survivors to another level, more work would need to be done. This includes:

- More research to ascertain whether the conceptual framework that has been developed in this study needs any additional supplementation for it to be fully applicable to survivors who are both better off and worse off in terms of their

personal status than the study sample. It has already been explained that there are limitations within the study sample and that the resultant framework may not be fully representative of the entire critical care population. Whilst changes experienced by survivors who are better off than the study sample may be covered by the conceptual framework because the framework delineates less severe changes and some positive changes, there is relatively little insight into what life is like for survivors who are worse off than the study sample, such as those who are too emotionally/psychologically traumatised to talk about the experience or survivors who have been discharged from hospital but are still physically too unwell to be interviewed. Therefore, more research needs to be done to check that the conceptual framework does not require any further supplementation where survivors who are worse off than the study sample are concerned. It may be that this group of survivors would never be successfully and/or adequately accessed, and other ways forward such as a systematic review of the literature identifying changes pertinent to them and interviews with their carers need to be used. In that case, it may be impossible to attain the same understanding of the survivors who have been left very disabled by their illness, simply because they are unable to explore the topic to the same extent given their condition. However, doing this research will still give some insights into the lives of such survivors, and help establish whether the patient-based conceptual framework constructed in this study can be used to select or develop a new measure as it currently stands.

- Further studies to determine whether the patient-based conceptual framework developed in this study is also broadly applicable to survivors who are not White British in ethnic origin. This is particularly pertinent if the framework were to be used to select or develop a critical care-specific measure for use in critical care populations of other ethnic origins (that is, of ethnic origins other than White British).
- Exploratory work and field-testing with survivors to establish the best strategies to facilitate the other recommendations for the critical care-specific measure (outlined in Section 10.2.2), if it were decided that these recommendations are to be taken up. This is particularly relevant for the recommendations that involve capturing survivors' perceptions and eliciting sensitive information from them.

10.6. Conclusion

The study fostered an understanding of the concept of HRQoL from the perspective of individuals who have personally gone through an episode of critical illness. This understanding is particularly pertinent to White British survivors who are/have been at least moderately affected by their illness, but are still well enough to be interviewed fairly intensively. It also established the extent to which the current expert consensus generic measures were sufficient in capturing survivors' HRQoL. Finally, the study gleaned insights on what survivors thought about the SF-36 and EQ-5D, including the difficulties they had faced while completing these questionnaires. The above knowledge enabled initial recommendations to be made on a critical care-specific measure.

However before selecting or developing this specific measure, the conceptual framework that has been developed by this study would need to be validated for certain groups of survivors, namely survivors who are not White British, survivors who are better off than the study sample and survivors who are worse off than the study sample. Only then should it be used as a basis for the critical care-specific measure. In addition, if it were decided that the other recommendations for the specific measure are to be implemented, further exploratory work and field-testing with survivors would have to be carried out to ascertain the most effective strategies for bringing these recommendations about.

Bibliography

1. Adamson J, Gooberman-Hill R, Woolhead G, Donovan J. 'Questerviews': using questionnaires in qualitative interviews as a method of integrating qualitative and quantitative health services research. *Journal of Health Services Research and Policy*. 2004 Jul;9(3):139-45.
2. Rubenfeld GD, Angus DC, Pinsky MR, Curtis JR, Connors AF, Jr., Bernard GR. Outcomes research in critical care: results of the American Thoracic Society Critical Care Assembly Workshop on Outcomes Research. The Members of the Outcomes Research Workshop. *American Journal of Respiratory and Critical Care Medicine*. 1999 Jul;160(1):358-67.
3. Angus DC, Carlet J. Surviving intensive care. Update in intensive care medicine. Vincent JL, editor 2004.
4. Jakob SM, Rothen HU. Intensive care 1980-1995: change in patient characteristics, nursing workload and outcome. *Intensive Care Medicine*. 1997 Nov;23(11):1165-70.
5. Angus DC, Carlet J. Surviving intensive care: a report from the 2002 Brussels Roundtable. *Intensive Care Medicine*. 2003 Mar;29(3):368-77.
6. Angus DC. Understanding the lingering consequences of what we treat and what we do. *Critical Care*. 2004 Apr;8(2):103-4.
7. Bullinger M, Anderson R, Cella D, Aaronson N. Developing and evaluating cross-cultural instruments from minimum requirements to optimal models. *Quality of Life Research*. 1993 Dec;2(6):451-9.
8. Black NA, Jenkinson C, Hayes JA, Young D, Vella K, Rowan KM, et al. Review of outcome measures used in adult critical care. *Critical Care Medicine*. 2001 Nov;29(11):2119-24.
9. Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. *Annals of Internal Medicine*. 1993 Apr 15;118(8):622-9.
10. Bowling A. *Measuring health: a review of quality of life measurement scales*: Open University Press; 2004.
11. Bowling A. *Measuring disease: a review of disease-specific quality of life measurement scales*: Open University Press; 2001.
12. Heyland DK, Guyatt G, Cook DJ, Meade M, Juniper E, Cronin L, et al. Frequency and methodologic rigor of quality-of-life assessments in the critical care literature. *Critical Care Medicine*. 1998 Mar;26(3):591-8.

13. Smith S, Sinclair D, Raine R, Reeves B. Health Care Evaluation. Maidenhead: Open University Press; 2005.
14. Quality of life and clinical trials. *Lancet*. 1995 Jul 1;346(8966):1-2.
15. Patrick DL, Deyo RA. Generic and disease-specific measures in assessing health status and quality of life. *Medical Care*. 1989 Mar;27(3 Suppl):S217-32.
16. Lamping DL, Schroter S, Kurz X, Kahn SR, Abenhaim L. Evaluation of outcomes in chronic venous disorders of the leg: development of a scientifically rigorous, patient-reported measure of symptoms and quality of life. *Journal of Vascular Surgery*. 2003 Feb;37(2):410-9.
17. Fayers P, Hays R. Assessing quality of life in clinical trials. Oxford: Oxford University Press; 2005.
18. Lamping DL, Schroter S, Marquis P, Marrel A, Duprat-Lomon I, Sagnier PP. The community-acquired pneumonia symptom questionnaire: a new, patient-based outcome measure to evaluate symptoms in patients with community-acquired pneumonia. *Chest*. 2002 Sep;122(3):920-9.
19. Hulsebos RG, Beltman FW, dos Reis Miranda D, Spangenberg JF. Measuring quality of life with the sickness impact profile: a pilot study. *Intensive Care Medicine*. 1991;17(5):285-8.
20. Chrispin PS, Scotton H, Rogers J, Lloyd D, Ridley SA. Short Form 36 in the intensive care unit: assessment of acceptability, reliability and validity of the questionnaire. *Anaesthesia*. 1997 Jan;52(1):15-23.
21. Kaarlola A, Pettila V, Kekki P. Performance of two measures of general health-related quality of life, the EQ-5D and the RAND-36 among critically ill patients. *Intensive Care Medicine*. 2004 Dec;30(12):2245-52.
22. Bowers C. It happened to an ICU nurse : an experience on the receiving end of intensive care. *Intensive and Critical Care Nursing*. 2004 Jun;20(3):174-7.
23. Andresen EM, Meyers AR. Health-related quality of life outcomes measures. *Archives of Physical Medicine and Rehabilitation*. 2000 Dec;81(12 Suppl 2):S30-45.
24. Ashing-Giwa KT. The contextual model of HRQoL: a paradigm for expanding the HRQoL framework. *Quality of Life Research*. 2005 Mar;14(2):297-307.
25. Coons SJ, Rao S, Keininger DL, Hays RD. A comparative review of generic quality-of-life instruments. *Pharmacoeconomics*. 2000 Jan;17(1):13-35.
26. Ferrans CE, Zerwic JJ, Wilbur JE, Larson JL. Conceptual model of health-related quality of life. *Journal of Nursing Scholarship*. 2005;37(4):336-42.

27. Haywood KL, Garratt AM, Fitzpatrick R. Quality of life in older people: a structured review of generic self-assessed health instruments. *Quality of Life Research*. 2005 Sep;14(7):1651-68.
28. Holcik J, Koupilova I. Defining and assessing health-related quality of life. *Central European Journal of Public Health*. 1999 Nov;7(4):207-9.
29. Naughton MJ, Shumaker SA. The case for domains of function in quality of life assessment. *Quality of Life Research*. 2003;12 Suppl 1:73-80.
30. Patrick DL, Bergner M. Measurement of health status in the 1990s. *Annual Review of Public Health*. 1990;11:165-83.
31. Measuring functioning and well-being: the medical outcomes study approach. Stewart AL, Ware JE, editors. Durham: Duke University Press; 1992.
32. Ware JE, Jr. The status of health assessment 1994. *Annual Review of Public Health*. 1995;16:327-54.
33. Ware JE, Jr. Conceptualization and measurement of health-related quality of life: comments on an evolving field. *Archives of Physical and Medical Rehabilitation*. 2003 Apr;84(4 Suppl 2):S43-51.
34. Adamson H, Elliott D. Quality of life after a critical illness-a review of general ICU studies 1998-2003. *Australian Critical Care*. 2005;18(2):50-60.
35. Bell D, Turpin K. Quality of life at three months following admission to intensive and coronary care units. *Clinical Intensive Care*. 1994;5(6):276-81.
36. Boyle M, Murgu M, Adamson H, Gill J, Elliott D, Crawford M. The effect of chronic pain on health related quality of life amongst intensive care survivors. *Australian Crit Care*. 2004 Aug;17(3):104-6, 8-13.
37. Brooks R, Kerridge R, Hillman K, Bauman A, Daffurn K. Quality of life outcomes after intensive care. Comparison with a community group. *Intensive Care Medicine*. 1997 May;23(5):581-6.
38. Broomhead LR, Brett SJ. Clinical review: Intensive care follow-up--what has it told us? *Critical Care*. 2002 Oct;6(5):411-7.
39. Capuzzo M, Bianconi M, Contu P, Pavoni V, Gritti G. Survival and quality of life after intensive care. *Intensive Care Medicine*. 1996 Sep;22(9):947-53.
40. Capuzzo M, Grasselli C, Carrer S, Gritti G, Alvisi R. Validation of two quality of life questionnaires suitable for intensive care patients. *Intensive Care Medicine*. 2000 Sep;26(9):1296-303.
41. Chaboyer W, Grace J. Following the path of ICU survivors: a quality-improvement activity. *Nursing in Critical Care*. 2003 Jul-Aug;8(4):149-55.

42. Chaboyer W. Intensive care and beyond: improving the transitional experiences for critically ill patients and their families. *Intensive and Critical Care Nursing*. 2006 Aug;22(4):187-93.
43. Cutler L, Brightmore K, Colqhoun V, Dunstan J, Gay M. Developing and evaluating critical care follow-up. *Nursing in Critical Care*. 2003 May-Jun;8(3):116-25.
44. Daffurn K, Bishop GF, Hillman KM, Bauman A. Problems following discharge after intensive care. *Intensive and Critical Care Nursing*. 1994 Dec;10(4):244-51.
45. Eddleston JM, White P, Guthrie E. Survival, morbidity, and quality of life after discharge from intensive care. *Critical Care Medicine*. 2000 Jul;28(7):2293-9.
46. Flaatten H. Follow-up after intensive care: another role for the intensivist? *Acta Anaesthesiologica Scandinavica*. 2005 Aug;49(7):919-21.
47. Gardner A, Sibthorpe B. Will he get back to normal? Survival and functional status after intensive care therapy. *Intensive and Critical Care Nursing*. 2002 Jun;18(3):138-45.
48. Garcia Lizana F, Peres Bota D, De Cubber M, Vincent JL. Long-term outcome in ICU patients: what about quality of life? *Intensive Care Medicine*. 2003 Aug;29(8):1286-93.
49. Griffiths RD, Jones C. Recovery from intensive care. *British Medical Journal*. 1999 Aug 14;319(7207):427-9.
50. Griffiths RD, Jones C. Intensive care aftercare. Griffiths RD, Jones C, editors. Oxford: Butterworth-Heinemann; 2001.
51. Griffiths J, Gager M, Alder N, Fawcett D, Waldmann C, Quinlan J. A self-report-based study of the incidence and associations of sexual dysfunction in survivors of intensive care treatment. *Intensive Care Medicine*. 2006 Mar;32(3):445-51.
52. Griffiths RD, Jones C. Seven lessons from 20 years of follow-up of intensive care unit survivors. *Current Opinion in Critical Care*. 2007 Oct;13(5):508-13.
53. Hall-Smith J, Ball C, Coakley J. Follow-up services and the development of a clinical nurse specialist in intensive care. *Intensive and Critical Care Nursing*. 1997 Oct;13(5):243-8.
54. Hayes JA, Black NA, Jenkinson C, Young JD, Rowan KM, Daly K, et al. Outcome measures for adult critical care: a systematic review. *Health Technology Assessment*. 2000;4(24):1-111.
55. Herridge MS, Cheung AM, Tansey CM, Matte-Martyn A, Diaz-Granados N, Al-Saidi F, et al. One-year outcomes in survivors of the acute respiratory distress syndrome. *New England Journal of Medicine*. 2003 Feb 20;348(8):683-93.

56. Hudson SJ, Brett SJ. Heterotopic ossification--a long-term consequence of prolonged immobility. *Critical Care*. 2006;10(6):174.
57. Hurel D, Loirat P, Saulnier F, Nicolas F, Brivet F. Quality of life 6 months after intensive care: results of a prospective multicenter study using a generic health status scale and a satisfaction scale. *Intensive Care Medicine*. 1997 Mar;23(3):331-7.
58. Maddox M, Dunn SV, Pretty LE. Psychosocial recovery following ICU: experiences and influences upon discharge to the community. *Intensive and Critical Care Nursing*. 2001 Feb;17(1):6-15.
59. Moran D, Elliott R, McKinley S. The Royal North Shore Hospital ICU nurse initiated telephone follow up service. *Intensive and Critical Care Nursing*. 2005 Feb;21(1):47-50.
60. Mundt DJ, Gage RW, Lemeshow S, Pastides H, Teres D, Avrunin JS. Intensive care unit patient follow-up. Mortality, functional status, and return to work at six months. *Archives of Internal Medicine*. 1989 Jan;149(1):68-72.
61. Rattray J, Crocker C. The intensive care follow-up clinic: current provision and future direction? *Nursing in Critical Care*. 2007 Jan-Feb;12(1):1-3.
62. Russell S. Who knows where they go? Quality of life after the intensive care. *Australian Nursing Journal*. 1996;3(8):20-2.
63. Sawdon V, Woods I, Proctor M. Post-intensive care interviews: implications for future practice. *Intensive and Critical Care Nursing*. 1995 Dec;11(6):329-32.
64. Strahan E, McCormick J, Uprichard E, Nixon S, Lavery G. Immediate follow-up after ICU discharge: establishment of a service and initial experiences. *Nursing in Critical Care*. 2003 Mar-Apr;8(2):49-55.
65. Walling A. Patient care in the aftermath of discharge from an ICU. *American Family Physician*. 2000;61(3):805.
66. Adamson H, Murgu M, Boyle M, Kerr S, Crawford M, Elliott D. Memories of intensive care and experiences of survivors of a critical illness: an interview study. *Intensive and Critical Care Nursing*. 2004 Oct;20(5):257-63.
67. Capuzzo M, Valpondi V, Cingolani E, Gianstefani G, De Luca S, Grassi L, et al. Post-traumatic stress disorder-related symptoms after intensive care. *Minerva Anestesiologica*. 2005 Apr;71(4):167-79.
68. Cuthbertson BH, Hull A, Strachan M, Scott J. Post-traumatic stress disorder after critical illness requiring general intensive care. *Intensive Care Medicine*. 2004 Mar;30(3):450-5.

69. Granja C, Lopes A, Moreira S, Dias C, Costa-Pereira A, Carneiro A. Patients' recollections of experiences in the intensive care unit may affect their quality of life. *Critical Care*. 2005 Apr;9(2):R96-109.
70. Hough CL, Curtis JR. Long-term sequelae of critical illness: memories and health-related quality of life. *Critical Care*. 2005 Apr;9(2):145-6.
71. Jones C, Griffiths RD. Long-term outcome from critical illness. *Anaesthesia & Intensive Care Medicine*. 2006;7(5):155-6.
72. Jones C, Griffiths RD, Macmillan RR, Palmer TEA. Psychological problems occurring after intensive care. *British Journal of Intensive Care*. 1994;4:46-53.
73. Kapfhammer HP, Rothenhausler HB, Krauseneck T, Stoll C, Schelling G. Posttraumatic stress disorder and health-related quality of life in long-term survivors of acute respiratory distress syndrome. *American Journal of Psychiatry*. 2004 Jan;161(1):45-52.
74. Lof L, Berggren L, Ahlstrom G. Severely ill ICU patients recall of factual events and unreal experiences of hospital admission and ICU stay--3 and 12 months after discharge. *Intensive and Critical Care Nursing*. 2006 Jun;22(3):154-66.
75. Meyer NJ, Hall JB. Brain dysfunction in critically ill patients--the intensive care unit and beyond. *Critical Care*. 2006;10(4):223.
76. Pattison N. Psychological implications of admission to critical care. *Br J Nurs*. 2005 Jul 14-27;14(13):708-14.
77. Scragg P, Jones A, Fauvel N. Psychological problems following ICU treatment. *Anaesthesia*. 2001 Jan;56(1):9-14.
78. Christie JD, Biester RC, Taichman DB, Shull WH, Jr., Hansen-Flaschen J, Shea JA, et al. Formation and validation of a telephone battery to assess cognitive function in acute respiratory distress syndrome survivors. *Journal of Critical Care*. 2006 Jun;21(2):125-32.
79. Gordon SM, Jackson JC, Ely EW, Burger C, Hopkins RO. Clinical identification of cognitive impairment in ICU survivors: insights for intensivists. *Intensive Care Medicine*. 2004 Nov;30(11):1997-2008.
80. Hopkins RO, Jackson JC. Long-term neurocognitive function after critical illness. *Chest*. 2006 Sep;130(3):869-78.
81. Jones C, Griffiths RD, Slater T, Benjamin KS, Wilson S. Significant cognitive dysfunction in non-delirious patients identified during and persisting following critical illness. *Intensive Care Medicine*. 2006 Jun;32(6):923-6.

82. Rothenhausler HB, Ehrentraut S, Stoll C, Schelling G, Kapfhammer HP. The relationship between cognitive performance and employment and health status in long-term survivors of the acute respiratory distress syndrome: results of an exploratory study. *General Hospital Psychiatry*. 2001 Mar-Apr;23(2):90-6.
83. Sukantarat KT, Burgess PW, Williamson RC, Brett SJ. Prolonged cognitive dysfunction in survivors of critical illness. *Anaesthesia*. 2005 Sep;60(9):847-53.
84. Papathanassoglou ED, Patiraki EI. Transformations of self: a phenomenological investigation into the lived experience of survivors of critical illness. *Nursing in Critical Care*. 2003 Jan-Feb;8(1):13-21.
85. Deja M, Denke C, Weber-Carstens S, Schroder J, Pille CE, Hokema F, et al. Social support during intensive care unit stay might improve mental impairment and consequently health-related quality of life in survivors of severe acute respiratory distress syndrome. *Critical Care*. 2006;10(5):R147.
86. Jacobs CJ, van der Vliet JA, van Roozendaal MT, van der Linden CJ. Mortality and quality of life after intensive care for critical illness. *Intensive Care Medicine*. 1988;14(3):217-20.
87. Jones C, Macmillan RR, Griffiths RD. Providing psychological support for patients after critical illness. *Clinical Intensive Care*. 1994;5(4):176-9.
88. Young E, Eddleston J, Ingleby S, Streets J, McJanet L, Wang M, et al. Returning home after intensive care: a comparison of symptoms of anxiety and depression in ICU and elective cardiac surgery patients and their relatives. *Intensive Care Medicine*. 2005 Jan;31(1):86-91.
89. Parno JR, Teres D, Lemeshow S, Brown RB, Avrunin JS. Two-year outcome of adult intensive care patients. *Medical Care*. 1984 Feb;22(2):167-76.
90. Qualitative research practice: a guide for social science students and researchers. Ritchie J, Lewis J, editors: SAGE Publications; 2003.
91. Qualitative research in health care. Pope C, Mays N, editors. London: BMJ Books; 1999.
92. Physical recovery. 2006 [cited 2010 07-06]; Available from: http://www.healthtalkonline.org/intensive_care/Intensive_care_Patients_experiences/Topic/1262/.
93. Emotional aspects of recovery. 2006 [cited 2010 13-06]; Available from: http://www.healthtalkonline.org/Intensive_care/Intensive_care_Patients_experiences/Topic/1263/topicList.

94. Recovering at home: affects on work. 2006 [cited 2010 13-06]; Available from:
http://www.healthtalkonline.org/Intensive_care/Intensive_care_Patients_experiences/Topic/1484/topicList.
95. Recovering at home: affects on family. 2006 [cited 2010 13-06]; Available from:
http://www.healthtalkonline.org/Intensive_care/Intensive_care_Patients_experiences/Topic/1483/topicList.
96. Jones C, Backman C, Capuzzo M, Flaatten H, Rylander C, Griffiths RD. Precipitants of post-traumatic stress disorder following intensive care: a hypothesis generating study of diversity in care. *Intensive Care Medicine*. 2007 Jun;33(6):978-85.
97. Jones C, Griffiths RD. Identifying post intensive care patients who may need physical rehabilitation. *Clinical Intensive Care*. 2000;11:35-8.
98. Miles MB, Huberman AM. *Qualitative data analysis: An expanded sourcebook*. 2nd ed: Sage; 1994.
99. Patton M. *Qualitative research and evaluation methods*. 3rd ed: Sage; 2002.
100. Ziebland S, McPherson A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness). *Med Educ*. 2006 May;40(5):405-14.
101. Smith G, Nielsen M. ABC of intensive care. Criteria for admission. *British Medical Journal*. 1999 Jun 5;318(7197):1544-7.
102. ICS. What is intensive care? [cited 2010 24-04]; Available from:
http://www.ics.ac.uk/patients_relatives/what_is_intensive_care.
103. Reasons for admission: Planned admissions. 2006 [cited 2010 24-04]; Available from:
http://www.healthtalkonline.org/Intensive_care/Intensive_care_Patients_experiences/Topic/1317/topicList
104. Reasons for admission: Emergency admissions. 2006 [cited 2010 24-04]; Available from:
http://www.healthtalkonline.org/Intensive_care/Intensive_care_Patients_experiences/Topic/1316/topicList.
105. Herridge MS. Morbidity and functional limitation in survivors of ARDS. In: Angus DC, Carlet J, editors. *Surviving intensive care Update in intensive care medicine*. Berlin: Springer; 2004.

106. Milbrandt EB, Angus DC. Bench-to-bedside review: critical illness-associated cognitive dysfunction--mechanisms, markers, and emerging therapeutics. *Critical Care*. 2006;10(6):238.
107. Horowitz SH. Executive functioning and learning disabilities. 2007 [cited 2009 July 4th]; Available from: <http://www.ncld.org/ld-basics/ld-aamp-executive-functioning/basic-ef-facts/executive-functioning-and-learning-disabilities>.
108. Baddeley A. Working memory: looking back and looking forward. *Nature Reviews: Neuroscience*. 2003 Oct;4(10):829-39.
109. Schacter DL. The seven sins of memory: how the mind forgets and remembers: Houghton Mufflin Harcourt; 2002.
110. Budson AE, Price BH. Memory dysfunction. *New England Journal of Medicine*. 2005 Feb 17;352(7):692-9.
111. WHO. Towards a common language for functioning, disability and health 2002.
112. Carr AJ, Gibson B, Robinson PG. Measuring quality of life: Is quality of life determined by expectations or experience? *British Medical Journal*. 2001 May 19;322(7296):1240-3.
113. Carr AJ, Higginson IJ. Are quality of life measures patient centred? *British Medical Journal*. 2001 Jun 2;322(7298):1357-60.
114. Ware JE, Jr., Gandek B. Overview of the SF-36 Health Survey and the International Quality of Life Assessment (IQOLA) Project. *Journal of Clinical Epidemiology*. 1998 Nov;51(11):903-12.
115. Ware JE, Jr., Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Medical Care*. 1992 Jun;30(6):473-83.
116. EuroQol--a new facility for the measurement of health-related quality of life. The EuroQol Group. *Health Policy*. 1990 Dec;16(3):199-208.
117. Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. *Social Science and Medicine*. 1999 Jun;48(11):1507-15.
118. Smith SC, Lamping DL, Banerjee S, Harwood R, Foley B, Smith P, et al. Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment*. 2005 Mar;9(10):1-93, iii-iv.

119. Dijkers MP. Individualization in quality of life measurement: instruments and approaches. *Archives of Physical Medicine and Rehabilitation*. 2003 Apr;84(4 Suppl 2):S3-14.
120. Ruta DA, Garratt AM, Leng M, Russell IT, MacDonald LM. A new approach to the measurement of quality of life. The Patient-Generated Index. *Medical Care*. 1994 Nov;32(11):1109-26.
121. Paterson C. Measuring outcomes in primary care: a patient generated measure, MYMOP, compared with the SF-36 health survey. *British Medical Journal*. 1996 Apr 20;312(7037):1016-20.
122. O'Boyle C, McGee H, Hickey A, Joyce C, Brown J, O'Malley K. The Schedule for the Evaluation of Individual Quality of Life. Administration Manual. Dublin: Royal College of Surgeons in Ireland; 1993.
123. Wiitavaara B, Bjorklund M, Brulin C, Djupsjobacka M. How well do questionnaires on symptoms in neck-shoulder disorders capture the experiences of those who suffer from neck-shoulder disorders? A content analysis of questionnaires and interviews. *BMC Musculoskeletal Disorders*. 2009;10:30.
124. Peters ML, Sorbi MJ, Kruise DA, Kerssens JJ, Verhaak PF, Bensing JM. Electronic diary assessment of pain, disability and psychological adaptation in patients differing in duration of pain. *Pain*. 2000 Feb;84(2-3):181-92.
125. The psychology of survey response. Tourangeau R, Rips LJ, Rasinski K, editors. Cambridge: Cambridge University Press; 2000.
126. Tourangeau R, Yan T. Sensitive questions in surveys. *Psychological Bulletin*. 2007 Sep;133(5):859-83.
127. Hayward P, Bright JA. Stigma and mental illness: A review and critique. *Journal of Mental Health*. 1997;6(4):345.
128. Rusch N, Angermeyer MC, Corrigan PW. Mental illness stigma: concepts, consequences, and initiatives to reduce stigma. *European Psychiatry*. 2005 Dec;20(8):529-39.
129. Dinos S, Stevens S, Serfaty M, Weich S, King M. Stigma: the feelings and experiences of 46 people with mental illness. Qualitative study. *British Journal of Psychiatry*. 2004 Feb;184:176-81.
130. Graham N, Lindesay J, Katona C, Bertolote JM, Camus V, Copeland JR, et al. Reducing stigma and discrimination against older people with mental disorders: a technical consensus statement. *International Journal of Geriatric Psychiatry*. 2003 Aug;18(8):670-8.

131. Goffman E. Stigma: Notes on the management of spoiled identity. Englewood Cliffs, NJ: Prentice Hall; 1963.
132. Mitchell K, Wellings K, Elam G, Erens B, Fenton K, Johnson A. How can we facilitate reliable reporting in surveys of sexual behaviour? Evidence from qualitative research. *Culture, Health and Sexuality*. 2007 Sep-Oct;9(5):519-31.
133. Freeman JA, Hobart JC, Thompson AJ. Does adding MS-specific items to a generic measure (the SF-36) improve measurement? *Neurology*. 2001 Jul 10;57(1):68-74.
134. Richards HM, Schwartz LJ. Ethics of qualitative research: are there special issues for health services research? *Family Practice*. 2002 Apr;19(2):135-9.
135. Pearse RM, Harrison DA, James P, Watson D, Hinds C, Rhodes A, et al. Identification and characterisation of the high-risk surgical population in the United Kingdom. *Critical Care*. 2006;10(3):R81.
136. Kagawa-Singer M, Padilla GV, Ashing-Giwa K. Health-related quality of life and culture. *Seminars in Oncology Nursing*. 2010 Feb;26(1):59-67.
137. Stewart AL, Napoles-Springer A. Health-related quality-of-life assessments in diverse population groups in the United States. *Medical Care*. 2000 Sep;38(9 Suppl):II102-24.
138. Wu AW. Quality-of-life assessment in clinical research: application in diverse populations. *Medical Care*. 2000 Sep;38(9 Suppl):II130-5.
139. Ashing-Giwa KT, Kagawa-Singer M, Padilla GV, Tejero JS, Hsiao E, Chhabra R, et al. The impact of cervical cancer and dysplasia: a qualitative, multiethnic study. *Psychooncology*. 2004 Oct;13(10):709-28.
140. Prinjha S, Field K, Rowan K. What patients think about ICU follow-up services: a qualitative study. *Critical Care*. 2009 Apr 1;13(2):R46.
141. Cox CE, Docherty SL, Brandon DH, Whaley C, Attix DK, Clay AS, et al. Surviving critical illness: Acute respiratory distress syndrome as experienced by patients and their caregivers. *Critical Care Medicine*. 2009;37(10):2702-8
142. Halcomb E, Daly J, Davidson P, Elliott D, Griffiths R. Life beyond severe traumatic injury: an integrative review of the literature. *Australian Critical Care*. 2005 Feb;18(1):17-8, 20-4.
143. Pattison NA, Dolan S, Townsend P, Townsend R. After critical care: a study to explore patients' experiences of a follow-up service. *Journal of Clinical Nursing*. 2007 Nov;16(11):2122-31.

144. Griffiths J, Waldmann C, Quinlan J. Sexual dysfunction in intensive care survivors. *British Journal of Hospital Medicine (Lond)*. 2007 Sep;68(9):470-3.
145. Adhikari NK, McAndrews MP, Tansey CM, Matte A, Pinto R, Cheung AM, et al. Self-reported symptoms of depression and memory dysfunction in survivors of ARDS. *Chest*. 2009 Mar;135(3):678-87.
146. Corrigan I, Samuelson KA, Fridlund B, Thome B. The meaning of posttraumatic stress-reactions following critical illness or injury and intensive care treatment. *Intensive and Critical Care Nursing*. 2007 Aug;23(4):206-15.
147. Davydow DS, Gifford JM, Desai SV, Bienvenu OJ, Needham DM. Depression in general intensive care unit survivors: a systematic review. *Intensive Care Medicine*. 2009 May;35(5):796-809.
148. Davydow DS, Gifford JM, Desai SV, Needham DM, Bienvenu OJ. Posttraumatic stress disorder in general intensive care unit survivors: a systematic review. *General Hospital Psychiatry*. 2008 Sep-Oct;30(5):421-34.
149. Lof L, Berggren L, Ahlstrom G. ICU patients' recall of emotional reactions in the trajectory from falling critically ill to hospital discharge: follow-ups after 3 and 12 months. *Intensive and Critical Care Nursing*. 2008 Apr;24(2):108-21.
150. Pattison N. Psychological implications of admission to critical care. *British Journal of Nursing*. 2005 Jul 14-27;14(13):708-14.
151. Ringdal M, Johansson L, Lundberg D, Bergbom I. Delusional memories from the intensive care unit--experienced by patients with physical trauma. *Intensive and Critical Care Nursing*. 2006 Dec;22(6):346-54.
152. Ringdal M, Plos K, Ortenwall P, Bergbom I. Memories and health-related quality of life after intensive care: a follow-up study. *Critical Care Medicine*. 2010 Jan;38(1):38-44.
153. Storli SL, Lindseth A, Asplund K. A journey in quest of meaning: a hermeneutic-phenomenological study on living with memories from intensive care. *Nursing in Critical Care*. 2008 Mar-Apr;13(2):86-96.
154. Thirugnanam S, Herridge MS. Physical consequences of critical illness. *British Journal of Hospital Medicine (Lond)*. 2007 Sep;68(9):477-81.
155. Thomas D. The journey back to effective cognitive function after brain injury. A patient perspective. *International Journal of Therapy & Rehabilitation*. 2009;16(9):497-501.
156. Akerman E, Fridlund B, Ersson A, Granberg-Axell A. Development of the 3-SET 4P questionnaire for evaluating former ICU patients' physical and psychosocial

problems over time: a pilot study. *Intensive and Critical Care Nursing*. 2009 Apr;25(2):80-9.

157. Gruber N. Beyond discharge: impairment after critical illness. *Registered Nurse*. 2008 May;71(5):29-32; quiz 3.

158. Herridge MS. Mobile, awake and critically ill. *Canadian Medical Association Journal*. 2008 Mar 11;178(6):725-6.

159. Jones C. Aftermath of intensive care: the scale of the problem. *British Journal of Hospital Medicine (Lond)*. 2007 Sep;68(9):464-6.

160. Brooks RB. Health related quality of life of intensive care patients: development of the Sydney Quality of Life Questionnaire. : University of New South Wales, Australia; 1998.

161. Kaarlola A, Pettila V, Kekki P. Quality of life six years after intensive care. *Intensive Care Medicine*. 2003 Aug;29(8):1294-9.

Appendix A

List of outcome studies included in literature review

1. Maynard S, Whittle J, Chelluri L, Arnold R. Quality of life and dialysis decisions in critically ill patients with acute renal failure. *Intensive Care Medicine*. 2003;29:1589- 93.
2. Broome A, Eisen G, Harland R, Collins B, Meyers W, Pappas T. Quality of life after treatment for pancreatitis. *Annals of Surgery*. 1996;223:665- 72.
3. Chrispin P, Scotton H, Rogers J, Lloyd C, Ridley S. Short Form 36 in the intensive care unit: assessment of acceptability, reliability and validity of the questionnaire. *Anaesthesia*. 1997;52:15- 23.
4. Ridley S, Chrispin P, Scotton H, Rogers J, Lloyd D. Changes in quality of life after intensive care: comparison with normal data. *Anaesthesia*. 1997;S2:195- 202.
5. Brenneman F, Redelmeier D, Boulanger B, McLellan B, Culhane J. Long-term outcomes in blunt trauma: who goes back to work? *The Journal of Trauma, Injury, Infection and Critical Care*. 1997;42:778- 81.
6. Weinert C, Gross C, Kangas J, Bury C, Marinelli W. Health-related quality of life after acute lung injury. *American Journal of Respiratory and Critical care Medicine*. 1997;156:1120- 8.
7. Schelling G, Stoll C, Haller M, Briegel J, Manert W, Hummel T, et al. Health-related quality of life and posttraumatic stress disorder in survivors of the acute respiratory distress syndrome. *Critical Care Medicine*. 1998;26:651- 9.
8. Kriwanek S, Armbruster C, Dittrich K, Beckerhinn P, Schwarzmaier A, Redl E. Long term outcome after open treatment of severe intra-abdominal infection and pancreatic necrosis. *Archives of Surgery*. 1998;133:140- 4.
9. Hopkins R, Weaver L, Pope D, Orme J, Bigler E, Larson-Lohr V. Neuropsychological sequelae and impaired health status in survivors of severe acute respiratory distress syndrome. *American Journal of Respiratory and Critical care Medicine*. 1999;160:50- 6.
10. Davidson T, Caldwell E, Curtis J, Hudson L, Steinberg K. Reduced quality of life in survivors of acute respiratory distress syndrome compared with critically ill control patients. *Journal of the American Medical Association*. 1999;281:354- 60.
11. Vedio A, Chinn S, Warburton F, Griffiths M, Leach R, Treacher D. Assessment of survival and quality of life after discharge from a teaching hospital general intensive care unit. *Clinical Intensive Care*. 1999;11:39- 46.
12. Heyland D, Hopman W, Coe H, Tranmer T, McColl M. Long-term health related quality of life in survivors of sepsis. Short Form 36: A valid and reliable

- measure of health-related quality of life. *Critical Care Medicine*. 2000;28(11):3599-605.
13. Pettila V, Kaarlola A, Makelainen A. Health-related quality of life of multiple organ dysfunction patients one year after intensive care. *Intensive Care Medicine*. 2000;26:1473- 9.
 14. Soran A, Chelluri L, Lee K, Tisherman S. Outcome and quality of life of patients with acute pancreatitis requiring intensive care. *Journal of Surgical Research*. 2000;91:89- 94.
 15. Eddleston J, White P, Guthrie E. Survival, morbidity and quality of life after discharge from intensive care. *Critical Care Medicine*. 2000;28:2293- 9.
 16. Flaaten H, Kvale R. Survival and quality of life 12 years after ICU. A comparison with the general Norwegian population. *Intensive Care Medicine*. 2001;27:1005- 11.
 17. Kvale R, Flaatten H. Changes in intensive care from 1987-1997-has outcome improved? A single centre study. *Intensive Care Medicine*. 2002;28:1110- 6.
 18. Wehler M, Geise A, Hadzionerovic D, Engujada A, Reulbach U, Hahn E, et al. Health-related quality of life of patients with multiple organ dysfunction: individual changes and comparison with normative population. *Critical Care Medicine*. 2003;31:1094- 101.
 19. Orme J, Romney J, Hopkins R, Pope D, Chan K, Thomsen G, et al. Pulmonary function and health-related quality of life in survivors of acute respiratory distress syndrome. *American Journal of Respiratory and Critical Care Medicine*. 2003;167:690- 4.
 20. Herridge M, Cheung A, Tansey C, Matte-Martyn A, Diaz-Granados N, Al-Saidi F, et al. One year outcomes in survivors of the acute respiratory distress syndromes. *New England Journal of Medicine*. 2003;348:683- 93.
 21. Kaarlola A, Pettila V, Kekki P. Quality of life six years after intensive care. *Intensive Care Medicine*. 2003;29:1294- 9.
 22. Kvale R, Flaaten H. Changes in health-related quality of life from 6 months to 2 years after discharge from intensive care. *Health and Quality of Life Outcomes*. 2003;1.
 23. Kvale R, Ulvik A, Flaaten H. Follow-up after intensive care: a single centre study. *Intensive Care Medicine*. 2003;29:2149- 56.

24. Graf J, Koch M, Dujardin R, Kersten A, Janssens U. Health-related quality of life before, 1 month after and 9 months after intensive care in medical cardiovascular and pulmonary patients *Critical Care Medicine*. 2003;31:2163- 9.
25. Kapfhammer H, Rothenhausler H, Krauseneck T, Stoll C, Schelling G. Post traumatic stress disorder and health-related quality of life in long term survivors of acute respiratory distress syndrome. *Amercan Journal of Psychiatry*. 2004;161:45- 52.
26. Kaarlola A, Pettila V, Kekki P. Performance of two measures of general health-related quality of life, the EQ-5D and the RAND-36 among critically ill patients. *Intensive Care Medicine*. 2004;30:2245- 52.
27. Elliott D, Mudaliar Y, Kim C. Examining discharge outcomes and health status of critically ill patients: some practical considerations. *Intensive and Critical Care Nursing*. 2004;20:366- 77.
28. Orwelius L, Nordlund A, Edll-Gustafsson U, Simonsson E, Nordlund P, Kristenson M, et al. Role of preexisting disease in patients' perceptions of health-related quality of life after intensive care. *Critical Care Medicine*. 2005;33:1557- 64.
29. Stricker K, Cavegn R, Takala J, Rothen H. Does ICU length of stay inflence quality of life? *Acta Anaesthesiologica Scandinavica*. 2005;49(975- 983).
30. Sukantarat K, Burgess P, Williamson R, Brett S. Prolonged cognitive dysfunction in survivors of critical illness. *Anaesthesia*. 2005;60:847- 53.
31. Hopkins R, Weaver L, Collingridge D, Parkinson R, Chan K, Orme J. Two year cognitive, emotional and quality of life outcomes in acute respiratory distress syndrome. *Amercan Journal of Respiratory and Critical Care Medicine*. 2005;171:340- 7.
32. Cuthbertson B, Scott J, Strachan M, Kilonzo M, Vale L. Quality of life before and after intensive care. *Anaesthesia*. 2005;60:332- 9.
33. Sluys K, Haggmark T, Iselius L. Outcome and quality of life 5 years after major trauma. *Joural of Trauma, Injury, Infection and Critical Care*. 2005;59:223- 32.
34. Granja C, Lopes A, Moreira S, Dias C, Costa-Pereira A, Carneiro A. Patients' recollections of experiences in the intensive care unit may affect their quality of life. *Critical Care*. 2005;9:R96- R109.
35. Granja C, Teixeira- Pinto A, Costa- Pereira A. Quality of life after intensive care- evaluation with EQ- 5D questionnaire. *Intensive Care Medicine*. 2002;28:898- 907.
36. Badia X, Diaz-Prieto A, Rue M, Patrick D. Measuring health and health state preferences among critically ill patients. *Intensive Care Medicina*. 1996;22:1379- 84.

37. Badia X, Diaz-Prieto A, Gorriz M, Hermand M, Torrado H, Farrero E, et al. Using the EuroQol- 5D to measure changes in quality of life 12 months after discharge from an intensive care unit. *Intensive Care Medicine*. 2001;27:1901- 7.
38. Sznajder M, Aegerter R, Launois R, Merliere Y, Guidet B, CubRea. A cost-effectiveness analysis of stays in intensive care units. *Intensive Care Medicine*. 2001;27:146- 53.
39. Lizana F, Bota D, Cubber M, Vincent J. Long-term outcome in ICU patients: what about quality of life? *Intensive Care Medicine*. 2003;29:1286-93.
40. Granja C, Morujao E, Costa-Pereira A. Quality of life in acute respiratory distress syndrome survivors may be no worst than in other ICU survivors. *Intensive Care Medicina*. 2003;29:1744- 50.
41. Granja C, Dias C, Costa-Pereira A, Sarmiento A. Quality of life of survivors from severe sepsis and septic shock may be similar to that of others who survive critical illness. *Critical Care*. 2004;8:R91- R8.
42. Hulsebos R, Beltman F, Miranda D, Spangenberg J. Measuring quality of life with the sickness impact profile: a pilot study. *Intensive Care Medicine*. 1991;17:285- 8.
43. Danis M, Patrick D, Southerland L, Green M. Patients' and families' preferences for medical intensive care. *Journal of the American Medical Association*. 1988;260:797- 802.
44. Bergner L, Bergner M, Hallstrom A, Eisenberg M, Cobb L. Health status of survivors of out-of-hospital cardiac arrest six months later. *American Journal of Public Health*. 1984;74:508- 10.
45. Sage W, Rosenthal M, Silverman J. Is intensive care worth it?- an assessment of input and outcome for the critically ill. *Critical Care Medicine*. 1986;14:777- 82.
46. Sage W, Hurst C, Silverman J, B W. Intensive care for the elderly: outcome of elective and non elective admissions. *Journal of American Geriatric Society*. 1987;35:312- 8.
47. Patrick D, Danis M, Southerland L, Hong G. Quality of life following intensive care. *Journal of General Internal Medicine*. 1988;3:218- 23.
48. Mundt D, Gage R, Lemeshow S, Pastides H, Teres D, Avrunin J. Intensive care unit patient follow-up: mortality, functional status and return to work at six months. *Archives of Internal Medicine*. 1989;149:68- 72.

49. Stambrook M, Moore A, Peters L, Deviaenes C, Hawryluk G. Effects of mild, moderate and severe closed head injury on long term vocational status. *Brain Injury*. 1990;4:183- 90.
50. Riether A, Smith S, Lewison B, Cotsonis G, Epstein C. Quality of life changes and psychiatric and neurocognitive outcome after heart and liver transplantation. *Transplantation*. 1992;54:444- 50.
51. Jones C, Hussey R, Griffiths R. A tool to measure the change in health status of selected adult patients before and after intensive care. *Clinical Intensive Care*. 1993;1993:160- 5.
52. Jones C, Griffiths G, Macmillan R, Palmer T. Psychological problems occurring after intensive care. *British Journal of Intensive Care*. 1994;4:46- 53.
53. Miranda D. Quality of life after cardiopulmonary resuscitation. *Chest*. 1994;106:524- 30.
54. McHugh L, Milberg J, Whitcomb M, Schoene R, Maunder R, Hudson L. Recovery of function in survivors of the acute respiratory distress syndrome. *American Journal of Respiratory and Critical Care Medicine*. 1994;150:90- 4.
55. Sawdon V, Woods I, Proctor M. Post-intensive care interviews: implications for future practice. *Intensive and Critical Care Nursing*. 1995;11:329- 32.
56. Tian Z, Miranda D. Quality of life after intensive care with the sickness impact profile. *Intensive Care Medicine*. 1995;21:422-8.
57. Wu A, Damiano A, Lynn J, Alzola C, Teno J, Landefield C, et al. Predicting future functional status for seriously ill hospitalised adults. *Annals of Internal Medicine*. 1995;122:342- 50.
58. Douglas S, Daly B, Brennan P, Harris S, Nochomovitz M, Dyer A. Outcomes of long term ventilator patients: a descriptive study. *American Journal of Critical Care*. 1997;6:99- 105.
59. Grady K, Jalowiec A, White-Williams C. Quality of life 6 months after heart transplantation compared with indicators of illness severity before transplantation. *American Journal of Critical Care*. 1998;7:106- 16.
60. Richmond T, Kauder D, Schwab C. A prospective study of predictors of disability at 3 months after non central nervous system trauma. *Journal of Trauma, Injury, Infection and Critical Care*. 1998;44:635- 43.
61. Short T, Buckley T, Rowbottom M, Wong E, Oh T. Long-term outcome and functional health status following intensive care in Hong Kong. *Critical Care Medicine*. 1999;27:51-7.

62. Lipsett P, Swoboda S, Dickerson J, Ylitalo M, Gordon T, Breslow M, et al. Survival and functional outcome after prolonged intensive care unit stay. *Annals of Surgery*. 1999;231:262- 8.
63. Chatila C, Kreimer D, Criner G. Quality of life in survivors of prolonged mechanical ventilatory support. *Critical Care Medicine*. 2001;29:737- 42.
64. Frick S, Uehlinger D, Zenklusen R. Assessment of former ICU patients' quality of life: comparison of different quality of life measures. *Intensive Care Medicine*. 2002;28:1405- 10.
65. Douglas S, Daly B, Gordon N, Brennan P. Survival and quality of life: short term versus long term ventilator patients. *Critical Care Medicine*. 2002;30:2655- 62.
66. Niskanen M, Ruokonen E, Takala J, Rissanen P, Aarno K. Quality of life after prolonged intensive care. *Critical Care Medicine*. 1999;27:1132- 9.
67. Shiell A, Griffiths R, Short A, Spiiby J. An evaluation of the costs and outcome of adult intensive care in two units in the UK. *Clinical Intensive Care*. 1990;1:256- 62.
68. Rowan K. Outcome comparisons of intensive care units in Great Britain and Ireland using APACHE II method. Oxford: University of Oxford; 1992.
69. Bell D, Turpin K. Quality of life at three months following admission to intensive and coronary care units. *Clinical Intensive Care*. 1994;5:276- 81.
70. Thiagarajan J, Taylor P, Hogbin E, Ridley S. Quality of life after multiple trauma requiring intensive care. *Anaesthesia*. 1994;49:211- 8.
71. Munn J, Willatts S, Tooley M. Health and activity after intensive care. *Anaesthesia*. 1995;50:1017- 21.
72. Trouillet J, Scheimberg A, Vuagnat A, Fagon J, Chastre J, Gibert C. Long term outcome and quality of life of patients requiring multidisciplinary intensive care unit admission after cardiac operations. *Journal of Thoracic and Cardiovascular Surgery*. 1996;112:926- 34.
73. Dixon J, Manara A, Willatts S. Patient and relative satisfaction with intensive care. Importance of duration and quality of life. *Clinical Intensive Care*. 1997;8:63- 8.
74. Gopal I, Bhonagiri S, Ronco C, Bellomo R. Out of hospital outcome and quality of life in survivors of combined acute multiple organ and renal failure treated with continuous venovenous hemofiltration/hemodiafiltration. *Intensive Care Medicine*. 1997;23:776- 2.
75. Nielsen D, Sellgren J, Ricksten S. Quality of life after cardiac surgery complicated by multiple organ failure. *Critical Care Medicine*. 1997;25:52- 7.

76. Montuclard L, Garrouste-Orgeas M, Timsit J, Misset B, Jonghe B, Carlet J. Outcome, functional autonomy and quality of life of elderly patients with a long term intensive care unit stay. *Critical Care Medicine*. 2000;28:3389- 95.
77. Combes A, Costa M, Trouillet J. Morbidity, mortality and quality of life and outcomes of patients requiring > 14 days of mechanical ventilation. *Critical Care Medicine*. 2003;31:1373- 81.
78. Hurel D, Loirat P, Saulnier, Nicolas F, Brivet F. Quality of life 6 months after intensive care: results of a prospective multicenter study using a generic health status scale and a satisfaction scale. *Intensive Care Medicine*. 1997;23:331- 7.
79. Ridley S, Wallace P. Quality of life after intensive care. *Anaesthesia*. 1990;45:808- 13.
80. Ridley S, Biggam M, Stone P. A cost utility analysis of intensive therapy. *Anaesthesia*. 1994 192- 196;1994(49).
81. Kerridge R, Glasziou P, K H. The use of "quality adjusted life years" (QALYs) to evaluate treatment in intensive care. *Anaesthesia and Intensive Care*. 1995;23:322- 31.
82. Slatyer M, James O, Moore P, Leeder S. Costs, severity of illness and outcome in intensive care. *Anaesthesia and Intensive Care*. 1986;14:381- 9.
83. Konopad E, Noseworthy T, Johnston R, Shustack A, Grace M. Quality of life measures before and one year after admission to an intensive care unit. *Critical Care Medicine*. 1995;23:1653-9.
84. Cooper A, Ferguson N, Hanley P, Meade M, Kachura J, Granton J, et al. Long term follow up of survivors of acute lung injury: lack of effect of a ventilation strategy to prevent barotrauma. *Critical Care Medicine*. 1999;27:2612- 21.
85. Kim S, Oh B, Lee J, Lim C, Shim T, Lee S, et al. Recovery from lung injury in survivors of acute respiratory distress syndrome: difference between pulmonary and extrapulmonary subtypes. *Intensive Care Medicine*. 2004;30:1960- 3.
86. Udekwu P, Gurkin B, Oller D, Lapio L, Bourbina J. Quality of life and functional level in elderly patients surviving surgical intensive care. *Journal of the American College of Surgeons*. 2001;193:245- 9.
87. Chelluri L, Pinsky M, Donahoe M, Grenvik A. Long term outcome of critically ill elderly patients requiring intensive care. *Journal of the American Medical Association*. 1993;269:3119- 23.

88. McHugh G, Havill J, Armistead S, Ullal R, Fayers T. Follow up of elderly patients after cardiac surgery and intensive care unit admission, 1991 to 1995. *New Zealand Medical Journal*. 1997;110:432- 5.
89. Vazquez-Mata G, Fernanadez R, Carmona A, Delgado-Rodriguez, Ruiz J, Pugnaire A, et al. Factors related to quality of life 12 months after discharge from an intensive care unit. *Critical Care Medicine*. 1992;20:1257- 62.
90. Fernandez R, Cruz J, Vazquez-Mata G. Validation of a quality of life questionnaire for critically ill patients. *Intensive Care Medicine*. 1996;22:1034- 42.
91. Vazquez-Mata G, Fernandez R, Aragon A, Carmona A, Mondejar E, Navarro P. Analysis of quality of life in polytraumatized patients two years after discharge from an intensive care unit. *Journal of Trauma, Injury, Infection and Critical Care*. 1996;41:326- 32.
92. Capuzzo M, Grasselli C, Gaetano G, Alvisi R. Validation of two quality of life questionnaires suitable for intensive care patients. *Intensive Care Medicine*. 2000;26:1296- 303.
93. Wehler M, Martus P, Geise A, Bost A, Mueller A, Hahn E, et al. Changes in quality of life after medical intensive care. *Intensive Care Medicine*. 2001;27:154- 9.
94. Weir L, Waldmann C. Long term follow up of ITU patients. *Auditorium*. 1994;40- 1.
95. Griffiths R, Jones C, Palmer T. Six month outcome of critically ill patients given glutamine-supplemented parenteral nutrition. *Nutrition*. 1997;13:295- 302.
96. Capuzzo M, Bianconi M, Contu P, Pavoni V, Gritti G. Survival and quality of life after intensive care. *Intensive Care Medicine*. 1996;22:947-53.

Appendix B

London School of Hygiene & Tropical Medicine

(University of London)

Health Services Research Unit

Department of Public Health & Policy

Keppel Street, London, WC1E 7HT

Tel (Mobile): +44 7899024915

Fax: +44 (0)20 7580 8183

Email: wan.lim@lshtm.ac.uk or wanchin.lim@gmail.com



Letter of Invitation to Participants

Study Title: Understanding the quality of life of critical care survivors

Dear....

I am writing to invite you to take part in a research study being carried out at the London School of Hygiene and Tropical Medicine, University of London. This is a study looking at the people's lives after they have been discharged from a critical care unit. We are particularly interested in finding out the issues survivors of critical illnesses have to deal with, including how these issues affect their day to day life. It is important to understand how patients' lives have been affected by their experience of being critically ill so that we can assess whether all aspects of life relevant and important to patients are being evaluated. This in turn will help us to better assess the impact of any medical intervention carried out in the critical care unit and in doing so, improve the delivery of critical care services.

We would be grateful if you would consider participating in this study. Full details of the study are in the attached information sheet. If you do decide to take part after reading the information sheet, you will be asked to consent verbally to being contacted by me. I will first contact you by telephone to answer any questions you may have and to ascertain that you still want to take part in the study. If you are still happy to proceed, I will arrange a convenient time and place for you to be interviewed.

If you would like any further information about this study, please do not hesitate to contact me on 07899024915 or email me on either wan.lim@lshtm.ac.uk or wanchin.lim@gmail.com.

Many thanks for taking the time to read this.

Regards,

Wan Chin Lim
MSc, MRCP, MB ChB

London School of Hygiene & Tropical Medicine

(University of London)

Health Services Research Unit

Department of Public Health & Policy

Keppel Street, London, WC1E 7HT

Tel (Mobile): +44 7899024915

Fax: +44 (0)20 7580 8183

Email: wan.lim@lshtm.ac.uk or wanchin.lim@gmail.com



Understanding the quality of life of critical care survivors

Information sheet for participants

You are invited to be interviewed as part of a research study. Before you decide whether to participate, it is important for you to understand why the research is being conducted and what it will involve. Please read the following information carefully and discuss it with others if you wish. Should you have any questions or need more information, please do not hesitate to contact Dr Wan Chin Lim, who is the main researcher on the study. Please take your time to decide whether or not you wish to participate in the study.

What is the purpose of this study?

Admission to a critical care unit often has wide ranging and sometimes long lasting effects on patients. It is becoming clear that patients value information on how being critically ill may affect their day to day living, their level of functioning, their well being and consequently, their quality of life after treatment. This information is also important to patients' relatives and friends. In order to provide this information, we need to know all the different areas of life which have been affected by the experience of being critically ill. Patients who have been through the experience themselves are the best people to help us gain a better understanding of this.

Your participation in this study will help us learn more about this important subject from the unique perspective of someone who has been through critical care. This information can then be used to produce better ways of assessing the impact of treatments in critical care. This will in turn improve the delivery of critical care services.

Why have I been chosen?

As mentioned above, we are interested in learning more about how critical illness has affected patients from their own perspective. As someone who has recently been discharged from the critical care unit in Wythenshawe Hospital, University of South Manchester NHS Foundation Trust, we are interested to hear about your experience since you left the unit.

Do I have to take part?

Participation in this study is entirely voluntary. You are also free to withdraw from the study at any time without having to give a reason. A decision not to participate or to withdraw at any time will not affect your clinical care in any way.

What do I have to do if I take part?

If you do decide to take part, you will be asked to consent verbally for the main researcher of this study to contact you by telephone. During this initial telephone contact, she will answer any questions you may have about the study and ascertain that you are still happy to take part in the study. If you are happy to proceed, she will arrange for you to be interviewed by her. Before the start of the interview, you will be asked to sign a consent form allowing the researcher to interview you. A copy of the consent form will be given to you to keep.

You will be interviewed to find out how being critically ill has affected your daily living and your quality of life since that time. Some background information such as your age, sex, health conditions and reason for admission to critical care will also be collected. During the course of the interview, you will be asked to fill in a questionnaire which has often been used to measure the quality of life of critical care patients. After filling in the questionnaire, you will be asked for your views on the questionnaire including whether you think the questionnaire covers all the aspects of quality of life important to you. The whole interview is likely to take 60 to 90 minutes. You may find that two separate interviews are easier for you to complete all this. The researcher will interview you at a time and place convenient to you (including your home) and the interview will be conducted entirely at your pace.

The entire interview will be audio taped to ensure that all the information given by you is accurately recorded. This will in turn help with the data analysis. The audio tapes will be stored securely in a locked cabinet and destroyed once the study is completed.

What are the possible benefits and risks of taking part?

It is unlikely that this research will personally benefit you but the information you provide us should help patients in the future. Although there do not appear to be any major risks associated with taking part in the study, some of the topics discussed during the interviews may potentially be upsetting to you. In the event of this happening, you can choose to terminate the interview. In all cases, whether you choose to end the interview or not, the interviewer will support you in any way she can. However, the interviewer is not a trained counsellor. Therefore, if she feels that you need more help, she will, with your permission, refer you back to the critical care unit at Wythenshawe Hospital, University Hospital of South Manchester NHS Foundation Trust where you receive your care. The unit runs a follow-up clinic which is conducted specifically to address any issues critical care survivors may have. In addition, with your permission, your general practitioner will also be informed.

What will happen to my treatment?

Whether you decide to participate in the study or not will make no difference to the care you will receive.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of this study will be kept strictly confidential. All the data recorded about you will have your name and address removed so that it will not be possible to identify you.

With your permission, your GP will be notified that you are taking part in this study. If you agree to them being informed, your GP will only be told that you are participating in the study- they will be told nothing about the answers to the questions.

What will happen to the results of the research study?

It is hoped that the results of this study will be published in medical journals and used to improve the way we assess the results of treatment. No patients will be identifiable in any published articles. Copies of the results will be made available to you if you want them.

Who is funding the research?

This study is funded by the Intensive Care Society, the UK's major professional body for critical care.

Who has reviewed the study?

The study has been reviewed and approved from an ethical point of view by the London School of Hygiene and Tropical Medicine ethics committee and the Stockport Research Ethics Committee.

What happens if I have any questions, concerns or complaints about the study?

If you have any questions concerning the study, please contact Wan Chin Lim, the main researcher of this study and/or Professor Nicholas Mays.

Contact information:

Dr Wan Chin Lim
c/o Ms Paula Fry
Health Services Research Unit
Department of Public Health and Policy
London School of Hygiene and Tropical Medicine
Keppel Street
London
WC1E 7HT
Tel: 07899024915
Email: wan.lim@lshtm.ac.uk or wanchin.lim@gmail.com

Professor Nicholas Mays
Health Services Research Unit
Department of Public Health and Policy
London School of Hygiene and Tropical Medicine
Keppel Street
London
WC1E 7HT
Tel: 0207 927 2222
Email: nicholas.mays@lshtm.ac.uk

If you have any comments, concerns or complaints about any aspect of the way you have been approached or treated during the course of this study, you should also contact Professor Nicholas Mays.

If you want advice from an independent source, you can contact the Research and Development Office for Wythenshawe Hospital, University of South Manchester NHS Foundation Trust.

Contact Information:

Miss Eleanor Thomas
Research and Development Office
Education and Research Centre
Wythenshawe Hospital
Southmoor Road
M23 9LT
Tel: 0161 291 5773

Thank you very much for taking the time to read this information sheet.

London School of Hygiene & Tropical Medicine

(University of London)

Health Services Research Unit

Department of Public Health & Policy

Keppel Street, London, WC1E 7HT

Tel (Mobile): +44 7899024915

Fax: +44 (0)20 7580 8183

Email: wan.lim@lshtm.ac.uk or wanchin.lim@gmail.com



Consent Form

Title of study: Understanding the quality of life of critical care survivors

Name of researcher: Wan Chin Lim

**Please Initial
on the dotted
line**

1. I confirm that I have read and understood the information sheet datedfor the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time and without giving any reason, without my treatment being affected.
3. I understand that all the information I provide for the purposes of this study will be kept strictly confidential.
4. I consent to my GP being informed that I am taking part in this study.
5. I consent to the interview being audio taped with a digital recorder and understand that the recording and the transcript of the interview will be stored securely and destroyed after analysis is completed.
6. I agree to being quoted anonymously in the results.
7. I agree to take part in the above study.

.....
Name of participant

.....
Date

.....
Signature

.....
Researcher

.....
Date

.....
Signature

London School of Hygiene & Tropical Medicine

(University of London)

Health Services Research Unit

Department of Public Health & Policy

Keppel Street, London, WC1E 7HT

Tel (Mobile): +44 7899024915

Fax: +44 (0)20 7580 8183

Email: wan.lim@lshtm.ac.uk or wanchin.lim@gmail.com



Study Title: Understanding the quality of life of critical care survivors

Dear Dr,

Re: [Patient's name and date of birth]

Your patient has kindly agreed to participate in an interview study which is being conducted to further our understanding of the concept of health related quality of life from the perspective of critical care survivors. Your patient has been recruited with the help of Dr Huw Maddock, Consultant in Anaesthetics and Critical Care through his involvement with the critical care unit in Wythenshawe Hospital, University Hospital of South Manchester NHS Foundation Trust and its follow-up services.

Your patient will be interviewed on up to two separate occasions in the next 2-4 weeks at his/her home, during which they will also fill in the [insert the HRQoL questionnaire]. Being a doctor who works in critical care and has a lot of interest in quality of life issues of critical care survivors, I will be conducting these interviews.

This study has been reviewed and approved from an ethical point of view by the London School of Hygiene and Tropical Medicine ethics committee and the Stockport Research Ethics Committee.

If you have any further questions regarding the study, please contact:

Dr Wan Chin Lim

Health Services Research Unit

Department of Public Health and Policy

London School of Hygiene and Tropical Medicine

Keppel Street

London WC1E 7HT

Telephone: 07899024915

Email: wan.lim@lshtm.ac.uk or wanchin.lim@gmail.com

Thank you for your time in this matter.

Yours sincerely,

Wan Chin Lim

Appendix C

Interview Guide

Administration: Face-to face in a private place of the participant's choosing (most likely to be their home)

(Obtain written informed consent from participant just before formally starting the interview. This includes going through the information sheet with the participant and giving them the opportunity to ask questions)

Introduction

We have just gone through the purpose of the study as well as what will be involved in this interview.

Do you have any more questions about what we are about to do before we start?

Please remember that you are free to take a break at any point during this interview, just let me know when you need to take a break. Also, if there is a particular question you do not wish to answer, let me know.

Are you happy to start?

(Notify the participant that the tape has been switched on and is recording)

Topic Guide

1. How are you feeling today?

Cover the activities which have been affected including participant's ability to look after themselves and run their lives¹

Cover aspects of life affected by admission to critical care²

2. Can you tell me a bit more about your health before the admission to critical care?

Cover information about chronic health conditions and previous limitations

3. Before moving on to asking you to fill in the questionnaire, I would like to collect some personal information about you, is that alright with you?

Cover the following details: age, marital status, number of children, housing (including details of who is living in the same household), employment, reason for admission to critical care, length of stay in critical care, length of hospital stay and length of time since hospital discharge.

I would like to ask you to fill in a questionnaire at this point. This questionnaire is used very frequently to measure the health and quality of life of critical care survivors. I am very interested to know what you think of the questionnaire. Do you want to take a break or do you want to continue? If you feel that you are getting tired, we can either take a break or I can come back another day.

Please answer all the questions in this questionnaire. If you have problems answering any of the questions, please make a note beside them. After you have completed the questionnaire, we will discuss these problems. I would also like to hear your thoughts and views of the questionnaire.

¹ Activities which may have been affected are listed on Page 1 of the appendix.

² The possible dimensions participants may bring up are listed in Page 2 of the appendix.

Do you have any questions for me before we start?

Questions for “questerview³” component of interview

1. Are there any questions you find difficult to answer? Why?

Cover how participants produce their answers, with particular emphasis on retrieval from memory and subsequent judgements and decisions about response categories.

2. What do you think about this questionnaire? Do you think that it accurately reflects how you think about your health and quality of life?

Cover the dimensions which constitute their HRQoL.

Cover how participants quantify the different dimensions of their HRQoL.

3. Does the questionnaire cover everything which is important and relevant to you?

Cover any dimensions which are relevant to participants but are not covered in the questionnaire.

Thank you very much for taking the time to participate in this interview.

Do you have any further questions for me?

(Notify participant that the tape recording has now been switched off and is no longer recording. Explain to participant that the tape recording will be transcribed to provide a written record for analysis. Inform participant that the study is likely to be completed by late 2009 and that the results are available upon request from the contact listed on the information sheet)

³ A form of cognitive debriefing in which a HRQoL measure currently recommended for this patient group (that is either the SF-36 or the EQ-5D) will serve as a focus point to trigger narratives and generate data relating to individuals' perceptions and definitions of HRQoL and its measurement, as well as providing insight into how well each measure 'works' with this patient group.

Appendix

Role functioning

1. Ability to look after themselves
 - a. Getting around, including getting to the toilet etc
 - b. Washing/showering
 - c. Personal grooming
 - d. Dressing
 - e. Eating and drinking
2. Ability to run their own lives
 - a. Shopping
 - b. Handling money
 - c. Preparing meals
 - d. Driving
3. Work

Dimensions

1. Physical

- a. Mobility/exercise tolerance (ability to move around the home and outside the home)
- b. Muscle dysfunction in other areas such as swallowing and cough
- c. Fatigue (tiredness)
- d. Numbness/paraesthesia (neuropathy/nerve palsies)
- e. Itching/pruritis
- f. Balance
- g. Coordination
- h. Pain/stiffness
- i. Communication/speech (long term tracheostomy)
- j. Appetite/nutrition
- k. Sleep
- l. Sexual functioning
- m. Specific organ dysfunction such as breathlessness or need for long term organ support such as dialysis
- n. Cosmetic concerns (alopecia, tracheostomy scars, scars from invasive monitoring, etc)

2. Psychological

- a. Anxiety/panic attacks
- b. Depression
- c. Guilt (about putting family through the experience)
- d. Anger and conflict within family
- e. Nightmares
- f. Post traumatic stress (flashbacks, anxiety/panic attacks, traumatic memories of critical care etc)
- g. Amnesia of events/loss of time causing distress
- h. Moving on, looking into future

3. Social

- a. Relationships with family and friends including any changes in how respondent relate to others or how others relate to respondent
- b. Support from family and friends, medical/nursing/auxiliary staff, work (degree of dependency)
- c. Social integration and whether they feel isolated from their social networks
- d. Living arrangements/residence
- e. Finances

4. Cognitive

- a. Memory
- b. Concentration

5. Spiritual

- a. Outlook in life
- b. Support from spirituality/church

Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Thank you for completing this survey!

For each of the following questions, please tick the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
▼	▼	▼	▼	▼
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Yes, limited a lot ▼	Yes, limited a little ▼	No, not limited at all ▼
-------------------------------	----------------------------------	-----------------------------------

- Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports..... ☐ 1 ☐ 2 ☐ 3
- Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf..... ☐ 1 ☐ 2 ☐ 3
- Lifting or carrying groceries ☐ 1 ☐ 2 ☐ 3
- Climbing several flights of stairs..... ☐ 1 ☐ 2 ☐ 3
- Climbing one flight of stairs..... ☐ 1 ☐ 2 ☐ 3
- Bending, kneeling, or stooping..... ☐ 1 ☐ 2 ☐ 3
- Walking more than a mile ☐ 1 ☐ 2 ☐ 3
- Walking several hundred yards ☐ 1 ☐ 2 ☐ 3
- Walking one hundred yards..... ☐ 1 ☐ 2 ☐ 3
- Bathing or dressing yourself..... ☐ 1 ☐ 2 ☐ 3

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

All of the time ▼	Most of the time ▼	Some of the time ▼	A little of the time ▼	None of the time ▼
-------------------------	--------------------------	--------------------------	------------------------------	--------------------------

- Cut down on the amount of time you spent on work or other activities ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
- Accomplished less than you would like..... ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
- Were limited in the kind of work or other activities..... ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
- Had difficulty performing the the work or other activities (for example, it took extra effort)..... ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼

- Cut down on the amount of time you spent on work or other activities ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
- Accomplished less than you would like ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
- c Did work or other activities less carefully than usual ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

7. How much bodily pain have you had during the past 4 weeks?

None	Very mild	Mild	Moderate	Severe	Very severe
▼	▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼

- Did you feel full of life?☐1.....☐2.....☐3.....☐4.....☐5
- Have you been very nervous?☐1.....☐2.....☐3.....☐4.....☐5
- Have you felt so down in the dumps that nothing could cheer you up?☐1.....☐2.....☐3.....☐4.....☐5
- Have you felt calm and peaceful?.....☐1.....☐2.....☐3.....☐4.....☐5
- Did you have a lot of energy?☐1.....☐2.....☐3.....☐4.....☐5
- Have you felt downhearted and low?☐1.....☐2.....☐3.....☐4.....☐5
- Did you feel worn out?☐1.....☐2.....☐3.....☐4.....☐5
- Have you been happy?☐1.....☐2.....☐3.....☐4.....☐5
- Did you feel tired?.....☐1.....☐2.....☐3.....☐4.....☐5

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

11. How TRUE or FALSE is each of the following statements for you?

Definitely true	Mostly true	Don't know	Mostly false	Definitely false
▼	▼	▼	▼	▼

- I seem to get ill more easily than other people.....☐1.....☐2.....☐3.....☐4.....☐5
- I am as healthy as anybody I know.....☐1.....☐2.....☐3.....☐4.....☐5
- I expect my health to get worse☐1.....☐2.....☐3.....☐4.....☐5
- My health is excellent☐1.....☐2.....☐3.....☐4.....☐5

Thank you for completing these questions!



By placing a tick in one box in each row, you indicate which statement best describes your own health status.

Mobility

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

Self-Care

- I have no problems with self-care
- I have some problems washing, dressing, etc.

Health Questionnaire

(English version for the UK)
(validated for use in Eire)

Usual Activities (e.g. work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

Pain/Discomfort

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

Anxiety/Depression

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

- I have no problems in walking about ☐
- I have some problems in walking about ☐
- I am confined to bed ☐

Self-Care

- I have no problems with self-care ☐
- I have some problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities*)

- I have no problems with performing my usual activities ☐
- I have some problems with performing my usual activities ☐
- I am unable to perform my usual activities ☐

Pain/Discomfort

- I have no pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have extreme pain or discomfort ☐

Anxiety/Depression

- I am not anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am extremely anxious or depressed ☐

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own
health state
today

